

**MEDICAL FUTILITY
AS AN ACTION GUIDE
IN NEONATAL END-OF-LIFE DECISIONS**

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DECLARATION

I, the undersigned, hereby declare that the work contained in this assignment is my own original work and that I have not previously, in its entirety, or in part submitted it at any University for a degree.

Signature

Date:

SUMMARY

This thesis discusses the value of medical futility as an action guide for neonatal end-of-life decisions. The concept is contextualized within the narrative of medical progress, the uncertainty of medical prognostication and the difficulty of just resource allocation, within the unique African situation where children are worse off today than they were at the beginning of the last century.

It is argued that the traditional medical paradigm, with its justification of an 'all out war' against disease and death, in order to achieve utopia for all, is outdated. Death in the neonatal intensive care unit is increasingly attributed to end-of-life decisions. Futile treatment could be considered a waste of scarce resources, contradicting the principle of nonmaleficence and justice, particularly in an African context.

The ongoing confidence in, and uncritical submission to the technological progress in medicine is understood as a defence and coping mechanism against the backdrop of the experience of life's fragility, suffering and the inevitability of death.

Such uncritical acceptance of the technological imperative could lead to a harmful fallacy that cure is effected by prolonging life at all cost. What actually occurs, instead, is the prolongation of the dying process, increasing suffering for all parties involved.

The historical development of the concept of medical futility is discussed, highlighting its applicability to the paradigmatic scenario of cardio-pulmonary resuscitation. Particular attention is given to ways in which the concept could endanger patient-autonomy by allowing physicians to make unilateral, paternalistic decisions.

It is argued that the informative model of the patient-physician relationship, where the physician's role is to disclose information in order for the patient to indicate her preferences, ought to be replaced by a more adequate deliberative model, where both

parties actively engage in an interactive deliberation for a plan of action. Both parties ought to accept moral responsibility. Such a model of deliberation has the added advantage of transcending the limitations of the participants to arrive at a higher-level solution, which is considered more than just a consensus.

It has been argued that medical progress has obscured the basic need for human compassion for the dying and for their loved ones. The literature furthermore reports that the quality of end-of-life care is unsatisfactory for both patients and their families. It is within this context that the concept of medical futility is positioned as a useful action guide.

As we do not have the luxury of withdrawing from the responsibility to engage in the deliberation of end-of-life decisions, such responsibility demands an increasing awareness of ethical dilemmas and a model of medical training where communication, conflict-resolution, inclusive history taking, with assessment of patient values and preferences, is focussed on. The capacity for empathetic care has to be emphasized as an integral part of such approach. Finally, in this thesis, the concept of medical futility is tested and applied to clinical case scenarios.

OPSOMMING

Hierdie tesis bespreek die waarde van mediese futiliteit as 'n maatstaf vir aksie in gevalle van neonatale 'einde-van-lewe' besluite. Die konsep word gekontekstualiseer binne die wêreldbeskouing van mediese vooruitgang, die onsekerheid van mediese prognostikering en die probleme wat geassosieer is met regverdige hulpbrontoekenning; spesifiek binne die unieke Afrika-situasie.

Dit word aangevoer dat die tradisionele mediese paradigma, met regverdiging vir voorkoming van siekte en dood ten alle koste, verouderd is. Sterftes in neonatale intensiewe sorgeenhede word toenemend toegeskryf aan 'einde-van-lewe' besluite. Futiele behandeling sou dus beskou kon word as 'n vermorsing van skaars hulpbronne, wat teenstrydig sou wees met die beginsels nie-skadelikheid ('non-maleficence') en regverdigheid.

Die volgehoue vertroue in en onkritiese aanvaarding van aansprake op tegnologiese vooruitgang in geneeskunde, kan beskou word as verdediging- en hanteringsmeganisme in die belewenis van lewenskwesbaarheid, lyding en die onafwendbaarheid van die dood.

Sodanige onkritiese aanvaarding van die tegnologiese imperatief kan tot 'n onverantwoordbare denkfout, naamlik dat genesing plaasvind deur verlenging van lewe ten alle koste, lei. Wat hierteenoor eerder mag plaasvind, is 'n verlenging die sterwensproses en, gepaard daarmee, toenemende lyding van al betrokke partye.

Die historiese ontwikkeling van die konsep van mediese futiliteit word bespreek met klem op die toepaslikheid daarvan op die paradigmadiese situasie van kardio-pulmonêre resussitasie. Spesifieke aandag word gegee aan maniere waarop die konsep pasiënte se outonomie in gevaar stel, deur die betrokke medici die reg te gee tot eensydige, paternalistiese besluitneming.

Die argument is dan dat die informatiewe model, waar die verhouding tussen die dokter en pasiënt gebaseer is op die beginsel dat die dokter inligting moet verskaf aan die pasiënt sodat die pasiënt 'n ingeligte besluit kan neem, vervang moet word met 'n meer toepaslike beraadslagende model, waar sowel die dokter as die pasiënt aktief deelneem aan interaktiewe beraadslaging oor 'n aksieplan. Albei partye word dan moreel verantwoordbaar. So 'n model van beraadslaging het die bykomende voordeel dat dit die beperkings van die deelnemers kan transcendeer. Sodoende word 'n hoër-vlak oplossing - iets meer as 'n blote consensus – te weeg gebring.

Die argument word ontwikkel dat mediese vooruitgang meelewing met die sterwendes en hul geliefdes mag verberg. Verder dui die literatuur daarop dat die kwaliteit van einde-van-lewe-sorg vir sowel die pasiënte as hul familie onaanvaarbaar is. Dit is binne hierdie konteks dat die konsep van mediese futiliteit kan dien as 'n maatstaf vir aksie.

Medici kan nie verantwoordelikheid vir deelname aan beraadslaging rondom einde-van-lewe besluitneming vermy nie, en as sodanig vereis die situasie toenemende bewustheid van sowel die etiese dilemmas as 'n mediese opleidingsmodel waarin kommunikasie, konflikthantering, omvattende geskiedenis-neming, met insluiting van die pasiënt se waardes en voorkeure, beklemtoon word. Die kapasiteit vir empatiese sorg moet weer eens beklemtoon word as 'n integrale deel van hierdie benadering.

Ten slotte, hierdie tesis poog om die konsep van mediese futiliteit te toets en toe te pas op kliniese situasies.

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TABLE OF CONTENTS

DECLARATION	2
SUMMARY	3
OPSOMMING	5
ACKNOWLEDGEMENT	7
 Chapter 1: INTRODUCTION	 10
1.1. AUTONOMY-PATERNALISM CONFLICT	13
1.2. GRAND NARRATIVE OF MEDICAL PROGRESS	15
1.3. MODERN UNCERTAINTY	16
1.4. RESOURCE ALLOCATION	17
 Chapter 2: THE CONCEPTUAL AND HISTORICAL DEVELOPMENT OF MEDICAL FUTILITY	 22
1.1. ORDINARY-EXTRAORDINARY MEANS	22
1.2. PROPORTIONAL-DISPROPORTIONAL MEANS	24
 Chapter 3: MEDICAL FUTILITY	 25
3.1. CARDIO-PULMONARY-RESUSCITATION (CPR) AS A PARADIGMATIC CASE	 25
3.2. DEFINITION OF MEDICAL FUTILITY	29
3.2.1. A QUANTITATIVE DEFINITION	29
3.2.2. A QUALITATIVE DEFINITION	29

3.3. ANTIFUTILITY ARGUMENTS	30
3.3.1. AMBIGUITY OF MEDICAL FUTILITY	30
3.3.2. IS FUTILITY A PHYSICIAN'S TRUMP CARD OVER PATIENT AUTONOMY?	33
3.4. BABY K: SANCTITY OF LIFE VERSUS FUTILITY	34
3.5. PERSONHOOD AND THE NO-PERSON CONCEPT	36
3.6. VALUE JUDGEMENTS	40
3.7. CONVERSATION VERSUS SILENCE	41
3.8. PROFESSIONAL INTEGRITY	41
3.9. PATIENT INTEGRITY AND THE ABUSIVE CHARACTER OF FUTILE TREATMENT	44
3.10. THE NEED FOR A DELIBERATIVE MODEL	45
3.11. AN AFRICAN PERSPECTIVE	48
3.12. FUTILITY POLICIES	50
 Chapter 4: CASE STUDIES	 51
4.1 AVOIDANCE OF EMERGENCY SURGERY IN TRISOMY 18 WITH LIFE-THREATENING ANOMALY	 51
4.2 A CASE OF ACTIVE EUTHANASIA FOR SHORT BOWEL SYNDROME	 55
 Chapter 5: CONCLUSIONS	 65
 FIGURES	 71
 REFERENCE LIST	 73

“AS WE GROW OLDER THE WORLD BECOMES STRANGER, THE PATTERN MORE
COMPLICATED OF DEAD AND LIVING.”

T.S. ELLIOT, “EAST COKER”

“THE PURPOSE OF MEDICINE IS TO DO AWAY WITH THE SUFFERING
OF THE SICK, TO LESSEN THE VIOLENCE OF DISEASE AND TO REFUSE
TO TREAT THOSE WHO ARE OVERMASTERED BY THEIR DISEASE.”

HIPPOCRATES

Chapter 1: INTRODUCTION

Birth and death are two poignant events that, in a unique way, converge in the Neonatal Intensive Care Unit (NICU) and represent two very significant human experiences. With advances in medical knowledge and technology, more infants are surviving and the death of the smallest and sickest has assumed increasing exposure and controversy. The underlying motivation in medicine has always been the battle against disease and death. It is the dream of modernity that through technical innovation and technical control of nature, man could achieve utopia. Natural causes of death have been banished and death has become ‘preventable’ in that death can be postponed indefinitely, creating an illusion of immortality.

The imperative to eradicate human suffering totally has become a societal priority against the backdrop of a narcissistic impulse to omnipotence (Richter, 1981: 129). The absolute self-confidence of our technological era could be understood as a defence mechanism against the experience of the fragility of life and as a mechanism for coping with disability and the inevitability of having to die.

Where medical technology can neither cure, nor prevent suffering, nor buy time to prolong meaningful life, as short as it may be, it is nevertheless able to postpone

death – sometimes indefinitely- and sustain the organism without improving the underlying diseased condition in any way. A consequence of the latter is that the boundary between life and death collapses. Medical therapy, keeping death at bay, may actually increase human suffering. “Such a case of a hopelessly suffering patient is only an extreme aspect of medical art, which - together with the power of the institution of the hospital and supported by the law, creates situations where it becomes questionable whether the rights (of the typically powerless and somehow ‘imprisoned’ patient) are respected or hurt...” (Jonas, 1987: 244).¹

In the fierce battle against disease and death, it is easy to lose perspective and to see both as absolute enemies that need to be kept at bay at all costs. This medical warfare comes at a very high financial and personal cost for all parties involved: patients, parents, staff as well as broader society.

Avery (1998) as reflected in figure 1 (page 71), demonstrates the cost/burden-efficacy relationship and that declining treatment efficacy is coupled with increased cost/burden (financial as well personal) leading to a marginal utility. On the one hand, society has to apply stringent criteria for the allocation of limited resources. On the other hand, patients are expecting increasingly high standards and innovative medical therapy. Medical professionals are directly exposed to these convergent societal demands, which create tension and can potentially clash with patient autonomy. It is within this context that I will be arguing that medical futility could be a useful tool for the critical analysis of marginal utility.

It is within the context of the above background that we need to understand that an increased percentage of babies are dying after a decision is made to withhold or withdraw life-sustaining treatment. In the early seventies, 14% of deaths within an American Neonatal Intensive Care Unit (NICU) followed the withdrawal of life-sustaining treatment (Duff & Campbell, 1973). A decade later, that number was

¹ My own translation from the German text: “Dieser Fall des hoffnungslos leidenden Patienten ist nur das Extrem in einem Spectrum aertzlicher Kunst, welche – im Verein mit der Anstaltsmacht des Krankenhauses und gestuetzt vom Gesetz – Situationen schafft, wo es fraglich wird, ob die Eigenrechte des (typisch machtlosen und irgendwie “gefangenen”) Patienten gewahrt oder verletzt werden”

increased to 20% to 50% (Whitelaw, 1986; Campbell, Lloyd, & Duffy, 1988) and in the nineties, the percentage has again dramatically increased to over 80% (De Leeuw et al., 1996; Kollée et al., 1999; Moskop, 1996). Staff and parents consider the making of such life and death decisions as one of the most challenging and painful experiences (Stinson & Stinson, 1983).

The question today is less about whether these babies– the very premature, the congenitally malformed, or the severely damaged – can be saved than whether this should be done, since the potentially adverse sequelae for these infants and for their families are well known and widely reported (McHaffie & Fowlie, 1996: 2). The goal of giving the infant a prospectively normal and healthy life, without pain and suffering, can often not be achieved. It therefore should be permissible to stop medical interventions in the hopelessly ill. The “hopelessly ill” may refer to “...lives that cannot be saved, that are irretrievably in the dying process...” It may also refer to lives “...that can be saved and sustained but in a wretched, painful, or deformed condition” (McCormick, 1974).

The case of Baby Doe could be paradigmatic for our discussion. In 1980, Baby Doe was born as a Downs’ syndrome baby with an oesophageal atresia, which could have been repaired surgically. At the parents’ request, nurses allowed Baby Doe to starve/dehydrate to death over 15 days. This case prompted US federal law to introduce the Child Abuse Amendments Act of 1984, which required anybody who was aware of medical abuse to whistle blow. The federal statute mandated that states “... establish programs and procedures in child protection service systems to respond to reports of medical neglect”. Medical neglect was defined as “withholding of medically indicated treatment from a disabled infant with a life-threatening condition” (Hall, 1996: 408).²

² Further definition of MEDICAL NEGLECT: Failure to respond to the infant’s life threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which in the treating physician’s medical judgment, will be *most likely to be effective in ameliorating or correcting* all such conditions (Child Abuse Amendments Act of 1984, cited in Hall, 1996).

Personal professional experience in the NICU has taught that seriously ill babies, with a poor and uncertain prognosis, are often given the ‘benefit of the doubt’ and are treated with all the possible technological options available, ‘until Nature takes its course.’ Such approach suggests an illusionary belief to be able to avoid end-of-life decision-making and an evasion of health professionals’ responsibilities. It also blurs the boundary between harm and the concepts of beneficence and non-maleficence, where suddenly the well intended treatment - by using technology at all cost - potentially creates exactly the opposite, namely inhuman suffering.

Within the debate of end-of-life decision-making, two main topics seem crucial and cause heated debate. It is the polarity of sanctity of life versus quality of life and medical futility. End-of-life decisions need a broad framework within which these different aspects can be debated critically (see figure 2 on page 72). This essay will mainly focus on the controversial and often misunderstood concept of medical futility by concluding that it is a worthwhile tool.

The discussion of the concept of medical futility will have to be put within the context of:

- The autonomy – paternalism conflict
- The grand narrative of medical progress
- Modern uncertainty
- Resource allocation and justice

1.1. THE AUTONOMY - PATERNALISM CONFLICT

Western debate of medical futility often takes place within a paradigm of conflict. This is particularly true for the debate about patient autonomy versus physician or expert paternalism.

Patient autonomy includes two essential conditions: “liberty (independence from controlling influences) and agency (capacity for intentional action)” (Beauchamp &

Childress, 1994: 121). Ethicists often confuse the role of paternalism through a “failure to differentiate between a principle of beneficence that competes with a principle of respect for autonomy and a principle of beneficence that incorporates the patient’s autonomy [in the sense that the patient’s preferences help to determine what counts as a medical benefit]” (Beauchamp & Childress, 1994: 272).

Paternalism nonetheless often involves some form of interference with or refusal to conform to patients’ preferences. “Paternalism, then, is the intentional overriding of one person’s known preferences or actions by another person, where the person who overrides, justifies the action by the goal of benefiting or avoiding harm to the person whose will is overridden” (Beauchamp & Childress, 1994: 27).

The Western World, predominantly English speaking countries and in particular the USA, is celebrating the predilection of patient autonomy over physician paternalism. As a result, it is understandable that the debate about medical futility causes anxieties that the acceptance of autonomy over paternalism, which has been so laboriously achieved, might progressively be turned upside down, allowing doctors to unilaterally override patient preferences by using futility arguments. “[It] was an attempt to convince society that physicians could use their clinical judgement or epidemiologic [sic] skills to determine whether a particular treatment would be futile in a particular clinical situation. The idea was that once such a determination had been made, the physician should be allowed to withhold or withdraw the treatment, even over the objections of a competent patient” (Helft, Siegler, & Lantos, 2000).

Within the broader African context and in particular, the South African context with the history of Apartheid, there is an additional complexity where paternalism has hardly been contested. Such a situation makes it easier for physicians to ignore and neglect patient autonomy. Apart from the cultural divide and lack of exposure to each other’s value systems, there is an underlying assumption that medical knowledge and technology could be too complex to understand for patients in general, and African patients in particular. At the same time, patients could easily develop unrealistic expectations from modern medicine, and adopt a cowed role trusting their doctors’

expertise unconditionally. It may then occur that the physician accepts such allocated trust into her authority uncritically. Consequently, end-of-life decisions are often made on their behalf.

In South Africa, a traditional, conservative and religious environment could favour such unreflective abuse of beneficial paternalistic authority.³

1.2. GRAND NARRATIVE OF MEDICAL PROGRESS

The utopian faith in modern technology is prevalent. Technology often imposes its imperative to treat all infants aggressively (Guillemin & Hommstrom, 1986). The faith in technology is grounded in the hope that through science we will find solutions to all our problems and that we will finally succeed. “The grand narrative of the modernist program assumed a logical and ordered universe whose laws could be uncovered by science. As the knowledge of these laws accumulated, it could be used to benefit humankind and eventually lead to the emancipation of humanity from poverty, sickness, and class and political servitude” (Polkinghorne, 1992: 147).

Within this narrative of progress, the researcher becomes a “... soldier in an army where the battles are fraught with difficulty, dedication is valorous, but victory is guaranteed. Each individual scientist makes his/her contribution – great or small – to the annihilation of ignorance and the establishment of truth [often equated with liberty and justice] for all” (Gergen, 1992: 25).

Technology however, has the tendency to be “... reductive, oversimplifying, impatient, and intolerant of ambiguity ...” (Cassell, 1993). It lures physicians into a false sense of certainty, where “[t]he image on the film - with its implication of objective certainty - comes to stand of the patient’s back pain, to the point where

³ It would be worthwhile and interesting to analyse this imbalance of power in general and specifically for the South African context, using Richter’s concept of the God Complex. Richter explains succinctly that such a complex was the result of a long process, which took place during the transition from the Middle Ages to the Modern Era. He describes the change from being a powerless child but within a secure relationship with God, to an attitude of autonomy, wanting to be in charge and responsible for everything, while being in a world of uncertainty (Richter, 1981).

greater weight is given to the image on the film than to the patient's pain" (Cassell, 1993).

1.3. MODERN UNCERTAINTY

The inherent reductionist tendency of technology has been exposed (Groeneweg, Sidler et al., 1991) and contrasted with uncertainty, which is increasingly accepted by physicians as a central problem. Medical reality is complex, so that one can easily find defects in physicians' personal knowledge as well as inadequacies in the profession at large. Uncertainty is also related to the fact that every decision is about the future, and the future is "...ineluctably uncertain..." and "... uncertainty can never go away because all of science, medical science is about generalities" (Cassell, 1993).

Patients have the tendency to resolve their own uncertainties by trusting physicians. This tendency increases the responsibility on the part of the physician. As a reaction to uncertainty, a multidisciplinary approach, where each discipline is well aware of its limitations, has developed. The dream of a complete and unifying theory of everything has become as elusive as it ever was and will be.

There is a tendency to overcome the mentioned uncertainty by dogmatism and applied rigid principles. These guiding principles become then absolute rules, i.e. that death is 'absolute evil' and life is 'absolute good'. The created dichotomy can lead to insensitivities when decisions about withdrawing or withholding of life-sustaining therapies have to be made. The imperative of technology to be used at all cost could contradict the four ethical principles of respect for autonomy, nonmaleficence, beneficence and justice.

1.4. RESOURCE ALLOCATIONS AND JUSTICE

Physicians generally shy away from economical arguments, but money spent on patients who are dying is less well spent than money spent on patients who have a chance to live and live well with a good quality of life. The main difficulty remains the uncertainty to know in advance, who will survive and who will not, and how quality of life should be assessed.

The discussion of justice and resource allocation within the South African context has to be conducted within a broader socio-political situation of African people who are still living in appalling conditions of poverty.⁴ Even in the first world countries, increasing medical costs prove an ever-increasing financial burden, becoming unaffordable even to the very rich.

Fleshman (2000) reports that the under-five year mortality rate for sub-Saharan Africa in the year 2000 was one hundred and seventy five per thousand - more than double the world average of eighty one per thousand and nearly thirty times higher than that of children in developed countries. Equally disturbing is the fact that half of the estimated five hundred and fifteen thousand women, who die annually from pregnancy or childbirth, are African woman. Chronic malnutrition is prevalent, with one in three Africans being malnourished. African children have the worst life chances in the world and they were worse off at the end of the last decade than they were at the beginning of it. Health services in particular have continuously deteriorated and are now less effective than ten years ago.

“In 1990, the international community declared, ‘together, our nations have the means and the knowledge to protect the lives and to diminish enormously the suffering of children.’ Twelve years later it is clear that, in fundamental ways, world leaders failed to deliver on their promises to improve the lives of Africa’s children” (Fleshman, 2000). It can therefore be argued that futile treatment, above all in the

⁴ Data released from the 1991 consensus demonstrates clearly the South African situation considering poverty.

developed as well as underdeveloped world (see marginal utility: figure 1 on page 71) is a waste of scarce resources and could contravene the principle of justice.

Decisions will have to be made on the macro- and micro-allocation level using standards appropriate for the African context. A note of caution should hint at the possible reality, that many so called futile treatments could stimulate progress in medicine and have a potential to become a tremendous resource in the future. Many expensive, experimental and innovative medical techniques could in time have a spin off. One such spin off could be that top specialists would stay in the public sector to do research in their field of medical interest. For example, there could be an argument for a worthwhile allocation of resources for a paediatric liver-transplantation program, which would have, through accumulative experience and research, beneficial spin-offs for other medical or even societal areas.⁵

Jacqueline Fortin (1990: 487, cited in Durand, 1999: 273) has asked how we ought to apply justice within the distribution of healthcare and health-services, particularly in a world, which, already for some time, has started to feel the burdens of advanced healthcare and treatment options. Three main different approaches, namely utilitarianism, libertarianism or egalitarianism have been described in answer to Fortin's question. Durand (1999: 273-277) has expanded these three aspects to eight different interpretations of the concept of justice,⁶ which I will now discuss in some detail.

1. *Personal merit. To each person according to merit.*

This theory highlights the importance of the individual and her performance. The theory is mainly applied within the educational system, the competitive world of sports and business. Being already a contested concept within its general application, it becomes even more difficult to apply it to the medical system, since many medical problems arise outside of one's individual control and are impossible to predict (Fortin, 1990: 488, cited in Durand, 1999: 274). As examples of conditions without

⁵ The only South African paediatric liver-transplant program has recently been severely curtailed by the only paediatric liver-transplant surgeon leaving the country to take up a Professorship in England.

⁶ The Belmont report proposes five and Beauchamp and Childress retain six (1994: 330).

an individual contribution to it, we could mention handicapped newborns, patients afflicted with a degenerative disease or patients involved in an accident. Such examples could be contrasted with self-inflicted conditions, such as conditions caused by abuse of tobacco, alcohol or drugs. A major difficulty, however, seems to be to determine the weight of the patient's personal responsibility for the behaviour or choices which have lead to these diseases (Durand, 1999: 274).

2. *Social value. To each person according to contribution.*

According to this perspective, civil servants, placed at the top of a social hierarchy, functionaries of the army defending a country, artists contributing to a country's fame and entrepreneurs running the economy successfully, would have a stronger right to healthcare resources than the majority of unknown citizens of humble upbringings (Fortin, 1990: 489, cited in Durand, 1999: 274). This concept would create grave injustices, mainly against the underprivileged (the handicapped, the aged and others). More importantly, the individual person's value would be reduced to her social role or production capacity, and she will have value only as a means to an end and not as an end in itself.

3. *The greatest good for the greatest number.*

According to this well accepted and prevalent utilitarian concept, a just allocation of resources would have to consider the distribution of the greatest good to the greatest number of people. Resources ought to be distributed in such a way that the community of citizens ought to get the greatest benefit possible. This approach however, penalises the terminally sick, because the terminal stage of disease is the least cost-effective (see figure 1: marginal utility).

Immediately, two potential injustices become apparent. On the one hand, developed countries have justifiably been accused that they abuse world resources disproportionately. According to Prof. S. Benatar (2002, personal communication), the top 20% of people are using 82.7% of the world's resources, whereby the bottom 20% has to be satisfied with only 1.7%. Fifty percent of the world population live on less than a dollar a day and use only ten dollars a year for healthcare, while

Americans use on average more than \$ 4000 a year. Eighty-nine percent of all the money is spent on 16% of the world population who carry 7% of disease burden. At the same time the Third World debt increases by 100 million dollars a year and South Africa alone has to pay back 2,5 times as much on interest than what it spends on its people's healthcare.

On the other hand, the same principle of injustice could be applied within a country itself, where academic institutions are using disproportionately far more resources per patient than hospitals do in the countryside. Further analysis could be undertaken using the concept of fairness.

4. *Respect free choice. To each person according to free-market exchanges.*

Everybody can freely choose what she wants to do with her property. The influence of the state needs to be kept to a minimum. Everybody can decide what type of care she wants by paying the necessary insurance costs. This understanding of justice risks to leave out minorities, the unfavoured, in short the poor of society.

5. *Priority to the most destitute. To each person according to need.*

John Rawls (1971) argues that justice consists of the restoration of the injustices and inequalities of one's fate. The role of the state would then be, according to this understanding, to privilege the most destitute. Justice means then to establish equal opportunities for all. It is then within this framework that we have to understand the paradigm shift from academic medicine to primary healthcare which has and is taking place in the present South African Healthcare System.

6. *Fundamental needs. To each according to her needs.*

According to this viewpoint, each ought to receive the resources she needs without taking into consideration her contribution to society according to her capacity. This conception of justice has the advantage to consider the fundamental equality of all people by acknowledging at the same time the real inequality of people's needs. Since human needs are without ends, they have to be restricted to the most fundamental and

essential. Nevertheless, how do we define and determine, within the framework of allocation of limited resources, what fundamental needs ought to be?

7. *Equality of treatment. To each person an equal share.*

The foundations of this conception of justice is that patients with similar disease conditions ought to be treated equally and that nobody can consider herself as an exception and have more rights than another. However consistent and widely accepted this theory might be, it is not without its critique. Within the framework of globalisation, no particular situation can be similar to another. Different regional or geographic peculiarities have to be taken into account. At the same time, one would have to ignore limited resources and for example make kidney dialysis equally available for all those in need.

8. *Reference to a chance event.*

“Justice consists of a denial to choose amongst equal individuals and let rather have chance a say, may it be through a system of lottery or adopting a rule such as first come first served” (Fortin, 1990: 490, cite in Durand, 1999: 277). This is the case for example with waiting lists (i.e. waiting list for liver-transplant). Such a conception of justice is based on the equality and the fundamental dignity of everybody as well as equal chances for all. Even though this interpretation of justice is sometimes favoured, one could ask whether it is not just representing a specific way of evading personal responsibility. The responsibility is shifted in this way from the physician in the academic hospital to the referring doctor in the peripheral hospital who will have to make the end-of-life decision because his patient has not been accepted into the ICU. It is questionable, if the referring doctor, often junior and less experienced, has the expertise to deal with such a complex situation.

Chapter 2: THE CONCEPTUAL AND HISTORICAL DEVELOPMENT OF MEDICAL FUTILITY

No concept is without its historical antecedents. The question of the appropriate means necessary to achieve a set treatment goal has been asked since ancient times. It seemed inappropriate, even to Hippocrates, to treat terminally ill patients. He said that there is “a time when we should stop treating those who are overmastered by their disease process” (Hippocratic Corpus, 1977). Plato expressed similar concerns when he said that a responsible physician “would not pander to those who should not be treated even though they may be rich as Midas” (Halliday, 1997).⁷

2.1. ORDINARY AND EXTRAORDINARY MEANS

The Catholic Church took ethical discussions about adequate means in health care seriously (Durand, 1999: 214). According to their doctrine, health is a fundamental good, a gift of God, where everybody has a duty to promote it by using the necessary means.

The Catholic Church argues that an ethical life demands those ordinary means that are generally required for a normal course of life: nutrition, appropriate rest and benign medical and surgical treatment that should not be excessively costly. To refuse such ordinary means, according to this view, equals suicide and/or active euthanasia. The notion of ordinary – extraordinary means has been popularised by Pope Pius XII in 1957: “It [the duty to conserve life and health] generally demands to use ordinary means (according to personal circumstances, place, time period and culture), indicating means which don’t impose any extraordinary burden for oneself or for others.” (Verspieren, 1987: 368, cited in Durand, 1999: 214).⁸

⁷Plato’s critique is still as pertinent an issue today in the private sector, where financial motivations may take precedence over beneficence.

⁸ My own translation of: “Mais il [le devoir de conserver la vie et la santé] n’oblige habituellement qu’à l’emploi des moyens ordinaires (suivant les circonstances de personnes, de lieux, d’époque, de

Extraordinary means are excessively costly, physically dehumanising, cause unacceptable physical or psychological pain, and have an excessive risk without an appreciable successful outcome. In this way, religious people do not believe that God demands of them to use extraordinary means to sustain their lives, whereby secular people arrived at the same conclusion by referring to the application of common sense.

One could argue that what is extraordinary today could easily become ordinary tomorrow. Examples of this process include the following: with the advent of anaesthesia, a risky procedure, causing excessive pain and suffering, has become an everyday procedure today. Furthermore, what is acceptable to one society might be unacceptable to another.⁹

A second example pertains to the use of antibiotics in an ordinary or extraordinary manner. How do we know when the use of antibiotics is ordinary and when does it become extraordinary? The prescription of antibiotics is customary and does not have to be expensive. Is it therefore ethical to treat infected terminal patients with antibiotics?

The terminology of ordinary and extra-ordinary means has always been unclear and ambiguous. It was therefore, replaced by the terminology of proportional and disproportional means.

culture), c'est-à-dire des moyens qui n'imposent aucune charge extraordinaire pour soi-même ou pour un autre."

⁹ It may be worthwhile to ponder the situation in Liberia today where trauma surgery has sometimes to be performed without any anaesthetic.

2.2. PROPORTIONAL AND DISPROPORTIONAL MEANS

The new terminology seems to reflect the contextual situation of patients better. The debate around using proportional means seems to indicate that the specific situation of a patient has been carefully analysed, in addition to all the costs and needs involved for specialized care. Means used are thus carefully balanced against projected outcomes. Again, the contribution of the Catholic authority was considerable: “After all one would appreciate the means to be used by putting the type of therapy used, its degree of complexity or risk, its costs, its possibilities of application, into relation with the expected results, equally having taken account of the patient’s state of affairs and his physical and moral resources.” (Verspieren, 1987: 420, cited in Durand, 1999: 215).¹⁰ Medical interventions are disproportional when the expected outcome is beyond a balanced relationship, when the risk analysis outweighs the benefit.

¹⁰ My own translation of: “De toute manière, on appréciera les moyens en mettant en rapport le genre de thérapeutique à utiliser, son degré de complexité ou de risque, son coût, les possibilités de son emploi, avec le résultat qu’on peut en attendre, compte tenu de l’état du malade et de ses ressources physiques et morales.”

Chapter 3: MEDICAL FUTILITY

Medical futility has increasingly replaced both above-mentioned concepts (Schneiderman, Jecker, & Jonsen, 1990). The main motive for this change has been an improved understanding of medical futility in terms of objectivity.

The term futility has its roots in the mythology of the Danaïdes (Jens, 1958: 14 & 30). All 50 daughters of king Danaos were forced to marry Danaos' twin brother's, Aegyptus, sons against their will. Danaos gave his daughters weapons and all, except Hypermnestra, killed their husbands on the wedding night. As punishment, they had to carry water in bottomless casks (futilis). The bottomless cask thus became a well-known Greek image, symbolizing useless labour and, on a more general level, indicating the apparent futility of all existence.

3.1. CARDIO-PULMONARY-RESUSCITATION (CPR) AS A PARADIGMATIC CASE

The history of CPR could serve as an illustrative example of the current 'futility-debate'. Bedell et al. (1983) enter this debate by reporting the inefficiency of CPR for specific subgroups of patients (metastatic disease, acute stroke, sepsis, renal failure, pneumonia and for those whose resuscitation took longer than thirty minutes).

CPR developed in the early 1960's within the coronary care units (CCU), where highly trained personnel and monitoring equipment were concentrated within these intensive care units (ICU) to monitor, otherwise healthy patients who had sustained serious damage to their hearts. Bedell et al. (1983) have shown that in the event of a fatal, in-hospital arrhythmia, CPR had a 50% success rate. Brody (1997) reported similar success rates for patients suffering cardiac arrest or arrhythmia from drug overdose or during anaesthesia.

The success of CPR has led to a typical and common development within medicine, namely the uncritical and indiscriminate use of technology.¹¹ This tendency seems rather to indicate that physicians want to believe in the applied technology, than that the technology used is actually effective.

CPR thus became a standard, knee jerk reaction to any patient who suffered a cardiac arrest within or outside the hospital. The information that there were subpopulations of patients in which the success rate of CPR was close to zero and therefore could appropriately be labelled futile, was ignored (Brody, 1997). Moss (1989) added that CPR was uniformly unsuccessful in the face of concomitant major organ system failure, overwhelming sepsis and metastatic cancer.

There seems to be a strong psychological need for both physicians and the public in general to overestimate the effectiveness of CPR (Wagg, Kinirons, & Stewart, 1995). Medical drama on television, depicting CPR as being highly successful, might have inadvertently influenced this general overestimation (Diem, Lantos, & Tulksy, 1996).

Recent data of the success of CPR paints quite a different and bleak picture. Basta et al. (1998) report that CPR succeeds at a rate of 10 to 20% for in-hospital cardiac arrest. This figure, however, decreases to fewer than 10% in patients over 65-years of age and 3.5% in patients over 85-years of age. The success in out-of-hospital arrests is even worse, however, with only 5% of patients able to be discharged home with 'intact' brain function. Elderly nursing home patients who suffer an out-of-hospital arrest are reported to survive in only 1 to 2% of cases.

These statistics are neither widely appreciated, nor consistently implemented. It is apparent that such knowledge could influence patients' expectations about their

¹¹The generalisation tendency in medical sciences, where effective technology in a particular context is uncritically applied to other conditions (see for example the popularity of minimal invasive procedures in the context of surgery), should be reflected on. There seems to be an inherent technological imperative, which demands its uncritical application. The necessary and important concepts, such as professional integrity, truth telling, and informed consent pertinent within this context are acknowledged as demanding attention, but due to space limitations falls beyond the scope of this assignment.

outcome. When researchers shared outcome data with people, their stated desire for CPR in a variety of medical scenarios decreased (Schonwetter et al., 1993).

It is difficult to generalize the predicted outcome of CPR in a heterogeneous group of patients, who have varying underlying ages, disease processes, and general health status. It is equally important to remember that such data cannot be directly extrapolated to sick neonates, since their potential for recovery is often extraordinary and unexpected.

In the very low-birth-weight infant (VLBW: birth weight < 1500g) many publications have reported contradictory results concerning the success or futility of CPR. Lantos et al. (1988, 1992) have claimed that survival after CPR for these babies was highly unlikely, a finding which was supported by some (Sood, 1992; LeBlanc, 1988; Willett, 1986) and countered by others (Korones, 1988; Richardson et al., 1988). Therefore Meadow et al. (1995) tested the outcome of CPR of two categories of babies, those who deteriorated from acute causes – defined as acute pneumothorax, pneumopericardium, plugged endotracheal tube; and those who deteriorated due to progressive causes – defined as everything else, but most commonly due to progressive hemodynamic deterioration associated with multiple organ failure. The first category had an acute new event in a sick child, which sometimes could be attributed to the treatment itself (iatrogenic) and the second category suffered from a progression of the underlying disease.

Their findings are intriguing and interesting. Seventy-four percent of 848 VLBW infants admitted to the NICU survived to discharge from the hospital. Seventy-six infants (9%) of all VLBW NICU admissions received CPR at some point after admission. Forty-eight (63%) were successfully resuscitated. Only 17 (22%), however, who received CPR could be discharged alive from the hospital. Eighty-six percent of infants died within 3 days of CPR; in contrast, 11% of the infants who died after CPR lived for three or more weeks before dying. Twenty-five (46%) required CPR for acute reasons, compared to 29 (54%) who received CPR for a progressive underlying cause.

Twelve of the 25 infants who received CPR for an acute cause survived until discharge from the hospital. In contrast, and this is interesting, none of the 29 infants whose CPR need was due to a progressive underlying condition survived to discharge from the hospital. In the authors' analysis "... it did not matter whether [the infants] were 400 or 1400g, whether they were 2 or 20 days old, whether or not they were septic, whether or not they had congenital malformations, or any other diagnostic distinctions that one might envision. If they received CPR without an "acute" cause, their prognosis was assured" (Meadow, Katznelson, Rosen, & Lantos, 1995).

Despite evidence to the contrary, the current default condition is to provide standard CPR for all infants. To criticize such attitude would expose oneself to severe polarisation. The data, however, seems to show that CPR for infants, who deteriorate from a progressive underlying disease, is unproven and should be labelled experimental. It is therefore the physician's responsibility to argue, "...why it should be offered, paid for, and above all, consented to. Parents could refuse this "experimental" therapy for any reason or for no reason at all" (Meadow et al., 1995).

The expanded analysis of CPR in adults and infants highlights another important point, which needs to be emphasized here, namely that no hard scientific data stands alone without its value judgement. The chosen threshold for a diagnostic test or for a successful therapy inadvertently includes value-judgements. It is therefore imperative to differentiate scientific fact from its contextual meaning and how and under what conditions the new knowledge or technology ought to be applied.

Doctors need to be cautious and humble when they insist on their expert authority, when they justify their decision-making on scientific data. Implicit value-judgements need to be critically reflected on as an important aspect of such decision-making.

3.2. DEFINITION OF MEDICAL FUTILITY

Most definitions of medical futility can be grouped into two main categories: the one emphasizing quantitative aspects and the other qualitative aspects (Schneiderman & Jecker, 1995; 1993; Schneiderman, Jecker, & Jonsen, 1990).

3.2.1. A QUANTITATIVE DEFINITION

The quantitative definition suggests that a treatment should be regarded as futile when it has not worked once during the last hundred attempts (Schneiderman, Jecker, & Jonsen, 1990). This is a purely quantitative account based on the probability that a treatment will not have the desired effect: i.e. a probability established by the empirical methods of medicine. Thus, if p is less than 0.01 ($p < 0.01$), a treatment option could be considered futile.

3.2.2. A QUALITATIVE DEFINITION

The qualitative definition of futility highlights the chasm between the achievement of an expected goal of treatment and its benefit to the patient. A futile treatment in this context is therefore one that “merely preserves permanent unconsciousness or that fails to end total dependence on intensive medical care” (Schneiderman, Jecker, & Jonsen, 1990).

Physicians should also differentiate between a therapeutic effect, i.e. limited to some part of the patient’s body (pure physiological definition of futility), and a benefit that improves the condition of the patient as a whole, allowing him to appreciate the outcome. Treatment with a therapeutic effect, but without benefit to a patient, is burdensome and could be labelled futile.

Some authors have endorsed the differentiation between quantitative and qualitative aspects of medical futility and between effect and benefit of a treatment (Callahan, 1991; Halliday, 1997).

In summary, the ethical presupposition of the applied concept of quantitative and qualitative futility is that futile means are not ethically required; with few exceptions, they should not be provided. There is no obligation whatsoever for the medical profession to offer futile treatment.

3.3. ANTIFUTILITY ARGUMENTS

3.3.1. AMBIGUITY OF MEDICAL FUTILITY

Even though medical futility has been increasingly applied as a decisive rule, several ethicists reject it outright due to its inherent ambiguities.

Lo (1995: 73-81) argues for a moderate position based on a careful review of some of the antifutility arguments. He believes that futility judgements could sometimes be justified but that the concept is "... fraught with confusion, inconsistency, and controversy" (Lo, 1995: 73). He grants that the concept of futility could make sense in some instances, when the treatment has no patho-physiological rationale;¹² the patient is not responding even though she is on maximal treatment; or the treatment has already previously been given without success, and it is nearly certain that further treatment will not achieve the goals for that patient.

He differentiates the above legitimate claim of futility judgements from other general uses of futility, where the likelihood of success is very small but not zero i.e. where the goals physicians perceive to be worthwhile cannot be achieved. In these cases, the patient's quality of life is unacceptable, or the prospective benefit is not worth the resources required.

¹²Here it would be interesting to review the ethics of complementary medicine.

Drane et al. (1993) succinctly summarize what they regard as futile treatment for babies. A treatment is futile when it “1 [sic] does not alter a person’s persistent vegetative state; 2 does not alter diseases or defects that make survival beyond infancy impossible; 3 leaves permanently unrestored a patient’s neurocardio-respiratory capacity, the capacity for a relationship, or moral agency; or 4 will not help free a patient from permanent dependency on total intensive care support.”

Waisel et al. (1995) have argued that the quantitative futility definition could be statistically interpreted to say that a therapy is futile when physicians are 95% confident that it would be successful no more than three out of a hundred times. They find this definition to be too loose and suggest a strict physiologic definition instead. They suggest that a treatment should be regarded futile if it does not achieve its physiological objective. If we apply this definition to CPR, it would imply that CPR is futile if it fails to achieve a heartbeat and circulation. CPR would, however, not be considered futile even if the patient consequently dies, if CPR achieved restoration of circulation albeit for the shortest period or if the patient survives without a chance to a quality of life.

They believe that their pure physiological definition is superior to Schneiderman’s (1990) differentiation between a qualitative and quantitative definition. They believe that their definition avoids a value judgement. It is however physiologically reductionistic, since it contains in itself a value judgement, which physicians ought to find suspicious, namely that “when we administer therapy, we care only what happens to the organs, and we do not care what happens to the patient” (Brody, 1997).¹³

Trotter (1999) argues that the concept of treatment failure needs to be seen in conjunction with the belief about the good of life, because the good of life will affect the choice of a futility threshold. “Thus conceptions of quantitative futility are not divorced from conceptions of the good.”

¹³ It is interesting that futility arguments are generally only applied to the initiation of CPR, completely ignoring that it is equally relevant to its termination. Both events however include a value judgement and are decisions, which doctors should never take lightly.

When treatment becomes futile, remains an unanswered question and attempts at quantification of treatment-outcome presents a difficulty. Our perception of futility can range from a probability of success of zero to just being poor. Poor probability needs to be defined first. Where should the cut-off point be? Should a treatment that is successful only in 1 to 2%, be regarded as having a poor probability for success, or should rather a probability of 13 to 15% be the benchmark? Who is going to be the judge and pass the final verdict?

We can easily appreciate the relativity of the futility concept when we use a business example as explanation. A business proposition with the probability of cashing in a million dollars in one in every 10^{20} attempts should rightly be called relatively futile when it is compared to another scheme where the probability is one in a 100. However, if we cash in only ten cents with a probability of winning one in a 100 times, the money making enterprise could be equally called futile. This example shows that the concept of futility can be evaluated from two different perspectives, namely in terms of probability or in terms of quality of treatment outcome.

Personal circumstances, such as the level of poverty, amount of deposit required for admission to the medical provider or the urgency of the need influence the judgement of futility. Confusing the different levels of futility judgements often triggers endless, insoluble disagreements between opposing parties.

Therefore, it is important that the concept of futility meets three conditions. Firstly, there needs to be a treatment goal. Secondly, different treatment options should offer a similar potential for recovery; and thirdly, there has to be some certainty that the chosen treatment will fail. If these three criteria are met, then we could say that a chosen treatment is futile considering a specific goal. The ethical literature is often confusing because the differing arguments are not so much about the futility of a treatment but about the morally inappropriateness of the treatment goals chosen (see discussion of CPR: page 26 onwards) .

The lack of information about the natural history of disease, which begins with its biological onset and may have specific outcomes – such as intact survival, survival with permanent disability, or death - is often lacking and attributes to the complexity of this discussion of futility. Medical prognostication is uncertain and poses another real problem for the futility debate.

What do we mean by prognosis and how do we arrive at it? For instance, surgery for a patient with a poor prognosis, suffering from advanced, terminal cancer is futile, whereas surgery for an inflamed appendix – amenable to excision and thus cure- is not. “Prognosis is a probabilistic judgement – specifically, an estimation of the relative probabilities that the patient will develop each of the alternative outcomes of the natural history of the disease. Because a prognosis consists of probabilities, it should not be made simply by informal recall of one’s previous clinical experience of similar cases. Rather, a prognosis should reflect a ‘best estimate’ derived from review of all valid prognostic studies which are applicable to the patient” (Sinclair & Torrance, 1995: 122).

Most currently available statistical models are not sufficiently accurate and predictive, particularly when they are applied to individual patients. Furthermore, existing predictive models do not seem to have improved accuracy of physicians’ clinical estimates of survival (Dotty & Walker, 2000).

In the context of such uncertainty, one’s professional frustration¹⁴ with a patient’s clinical response to perceived indicated and adequate treatment, one’s difficulty in accepting the patient’s outcome and quality of life could very easily be confused with the scientific assessment of her probability to improve, and the consequential labelling of such treatment as futile. Futility judgements could thus quite easily become mistaken rationalisations and projections of feelings of professional inadequacy, failure and guilt.¹⁵

¹⁴ Often experienced as personal failure, leading to guilt feelings.

¹⁵ It could be a worthwhile endeavour to investigate such rationalisations further.

3.3.2. IS FUTILITY A PHYSICIAN'S TRUMP CARD OVER PATIENT AUTONOMY?

Antifutility arguments are often championed by ethicists who fear that physicians may use futility arguments unilaterally, virtually turning the clock back to a time when paternalism granted physicians unlimited power in making treatment decisions, thereby severely restricting patients' autonomy through dominance of expert opinion.

Angell (1994) presents arguments, which seem to support such fears. She argues that patients who are diagnosed with permanent loss of consciousness should be refused medical treatment in order to prevent demoralized caregivers from being forced to provide care, which they believe to be futile, and a waste of valuable resources. She further suggests changing the definition of death to include a diagnosis of permanent unconsciousness. According to her argument, treatment should be withdrawn unilaterally after a mandatory yet limited period of medical treatment for unconscious people, regardless of family objections.

The American Thoracic society seems to have embraced such a conclusion. They show their agreement with Angell, by issuing a policy statement declaring that treatment should be considered futile "... if reasoning and experience indicate that the intervention would be highly unlikely to result in a meaningful survival for the patient", and assert that a "... health care institution has the right to limit a life-sustaining intervention without consent" (American Thoracic Society, 1991: 481).

3.4. BABY K: SANCTITY OF LIFE VERSUS FUTILITY

The history of baby K could be used as a paradigmatic demonstration of such a futility debate.

Baby K was born in 1992 as an anencephalic (i.e. missing cerebral cortex with absent higher brain function) infant girl to a deeply religious mother who insisted, against all

protestations that everything should be done to keep the baby alive (Annas, 1994). Subsequently, baby K was repeatedly admitted to hospital and ventilated for respiratory failure.

Eventually the mother found everybody opposing her: the father, the doctors involved in the case, the local Ethics Committee, the hospital administration, and the relevant professional medical societies, namely the American Academy of Pediatrics and the Society of Critical Care Medicine.

The mother hoped for a miracle, believing that God was to determine the time and place of her child's death. The physicians argued that the child was without a cerebral cortex, irreversibly in coma, incapable of self-awareness, and with a hopeless prognosis.

The hospital administration, in its frustration at being compelled to give 'non-indicated' medical care, went to court and asked for permission to withdraw the respiratory support, citing futility and the standards of medical care for anencephalic infants as arguments supporting their position. The court ruled in favour of the mother and ordered that ventilation should continue. The hospital appealed to a panel of three judges of the Fourth Circuit Court of Appeals, which resulted in a split vote. Two judges argued that respiratory failure was the relevant diagnosis, that it could be treated, and that a respirator was effective therapy. The third judge held that anencephaly was the fundamental diagnosis, that it was untreatable, and that the standard of medical care for anencephaly did not include ventilator support. The original decision was upheld.

This debate clearly illustrates the point under scrutiny, namely the unrecognised difference in the treatment goal of the different parties. The matter was ultimately sent for appeal to the US Supreme Court, which again upheld the judgement of the lower courts.

A number of authors, summarized by Stephen (1995), have commented on the unlimited authority that this ruling seems to give to the demands of parents that may be beyond the standards of medical practice and that the responsible physician ought to oppose this.

Annas (1994: 1542) argues that physicians should act according to their professional convictions instead of letting the courts decide. He says: "...to avoid these scenarios, physicians must work toward a third, in which they not only set standards for medical practice, but also follow them. Physicians cannot expect parents, trial judges, insurance companies, or government regulators to take practice standards more seriously than they do themselves. If physicians cannot set standards for the care of anencephalic infants and adhere to them, standard-setting by physicians is a dead issue."

The controversy around baby K highlights another important concern, namely the 'no-person concept' (Trotter, 1999). There has to be a person to benefit from non-futile treatment otherwise the treatment ought to be referred to as futile. The 'no-person' concept presents however new controversies about what an acceptable definition and understanding of personhood should constitute.

3.5. PERSONHOOD AND THE NO-PERSON CONCEPT

Engelhardt (1986) defines a person as an autonomous, self-conscious, rational and moral being. He distinguishes such a person from a human being. He denies that biological factors such as the human genome by themselves are enough to constitute a person. Not all human beings are therefore automatically persons. "The foetus, infants, the profoundly mentally retarded, and the hopelessly comatose provide examples of human non-persons" (Engelhardt 1986: 107).

According to this definition, one could then suggest that two categories of human beings exist within the broader human community, namely persons and non-persons;

some are not yet, but have the potential to become persons; others are no longer persons, after they have been such; and some will never be a person. According to him, only persons have the right to unconditional respect. "The principle of autonomy and its elaboration in the morality of mutual respect applies only to autonomous beings. The morality of autonomy is the morality of persons. For this reason it is nonsensical to speak of respecting the autonomy of foetuses, infants, or profoundly retarded adults, who have never been rational" (Engelhardt, 1986: 108). The implication of such an argument would be that society is not obliged to sustain the life of non-persons at all cost.

Upon scrutiny, his thesis seems to be ambiguous. On the one hand, he tries to take account of the facts, that there is a difference between a few day old foetus, an anencephalic infant, a comatose patient and an autonomous and rational human being. The strength of Engelhardt's doctrine is then that it keeps the unconditional care for all human persons intact. On the other hand, his argument implies that lesser human beings become dependent on the goodwill of the community of persons. Lesser human beings become in this way dependant on the subjective (relative) value that is attached to them by the community of persons. Objective criteria have vanished in this way and the unity of all humanity is split into two different categories that seem to demand different respect. His doctrine refuses to acknowledge biological criteria to define personhood, and replaces them by psychological ones. Whether this is an improvement remains an unanswered question.

Fletcher (1972, cited in Singer, 2001: 127, & 1974, cited in Durand, 1999: 373-374), a Protestant theologian, argues similarly. He initially proposes fifteen indicators defining a person, which he then consolidates to four: self-awareness, capacity to interact, happiness and neocortical function. Finally, he retains a single decisive criterion for personhood, namely neocortical function.

Some critical questions arise from Fletcher's position. Firstly, the coherence of his indicators of personhood could be questioned. Are these listed criteria of equal importance? Secondly, the character of some of the items listed is relative and

subjective. For example, how should one appreciate or categorize happiness? Finally, is it necessary to fix impossible boundaries at all costs?

Both above theories of personhood are reductionist. In their definition of a person, the theory is centred on a specific criterion that is directly operational. It was Singer (2002), who dared to apply the logic of these doctrines rationally and took it one-step further to include higher developed animals, such as the great apes, into the community of persons.

He (1995; 2001) argues, that beings with the mental capacity to see themselves as existing over time, are persons. Killing them is therefore morally wrong. While all normal adult human beings and some non-human animals, such as the great apes, could be regarded according to Singer as persons; many animals and some human beings, such as newborn infants and the severely brain-damaged, are not persons in a moral sense. While their capacity to experience pain makes them morally considerable, killing them painlessly cannot be considered directly wrong.

“The new vision leaves no room for the traditional answer to these questions [who is a person?], that we human beings are a special creation, infinitely more precious, in virtue of our humanity alone, than all other living things. In the light of our new understanding of our place in the universe, we shall have to abandon that traditional answer, and revise the boundaries of our ethics. One casualty of that revision will be any ethic based on the idea that what really matters about beings is whether they are human “ (Singer, 1995: 183). This will have far-reaching implications, “... not only on our relations with nonhuman animals, but on the entire traditional *sanctity of life ethic*.”¹⁶ A thorough critique of the sanctity of life ethics has already been discussed by Helga Kuhse (1987).

The conclusion can only be that physicians do not have to sustain a non-person through all technical means available. Such medical attempt could be labelled futile, even amoral. Not everybody will however accept above definitions of what

¹⁶ Italics inserted by me.

constitutes a person and it seems that conflicts between patients, their families and physicians are inevitable.

There are other more holistic interpretations of personhood such as the one by the French philosopher, Lucien Sève (1994, cited in Durand, 1999: 375-381). Together with the Consultative National Ethics Committee [Comité Consultatif National d'Éthique = CCNE] in France, they seem to take a different approach from the philosophers mentioned above. Instead of being reductionist and defining a person according to a specific operational criterion, Sève aims at deploying all aspects of a person (the biological individual, the psychosocial personality, and the subject of law and particular of morals). In this way, he tries to show that these differing aspects fit together to constitute a singular unity. Such a person is complex but unified, autonomous and open to other persons, even to future generations at the same time.

Sève differentiates three dimensions (the biological individual, the psychosocial personality, and the subject of law and in particular of morals) relevant to a person. In the first instance, a person is a biological individual, an indivisible organic totality that is more than its parts (genes, cells, synapses, etc). The person is an integrating whole of all the multiple elements that each in itself has the tendency to conserve the being. The biological individual is a unique singularity and at the same time, all the elements of our species can be found in it. "We can therefore objectively recognize that the individual is an irreducible identity, which is at once the same and different from all human beings (i.e. genome and central nervous system)" (Sève, 1994: 26, cited in Durand, 1999: 376).¹⁷

Secondly, he recognises that a person has a psychosocial personality that gives her a specific identity of psycho-affective and social dimensions. Thirdly, he introduces the concept of the subject, the subject of law but more fundamentally the ethical subject.

¹⁷ My own translation of: "Nous devons donc objectivement parlant reconnaître à l'individu une irréductible identité, qui le fait d'emblée même et autre que chaque être humain (i.e. genome et système nerveux centrale)."

These three aspects of a person (biological individual, psychosocial personality and juristic - ethical subject) are neither interchangeable nor juxtaposed; they are related through a unity that is the person. In this way, the person transcends scientific facts, (biological as well as psychological ones) to arrive at values. As valuable a critical evaluation of Singer's conception of a person would be by applying Sève's more holistic one, there is no space for it in this essay.

3.6. VALUE JUDGEMENTS

I have argued that physicians seem not to be able to evade the responsibility of making value judgements, because of their role in diagnosing and prognosticating disease. There is, however, the danger of mistaking value judgements for factual or scientific expertise. It is essential that we become aware of two types of judgements, both of which physicians regularly have to make.

Firstly, judgements based on true technical knowledge, in which physicians can legitimately claim expertise; and secondly, value judgements where physicians have the obligation to respect the wishes of the autonomous patient, her family, community and society at large (Brody, 1997: 3).

With the above in mind one can appreciate that futility judgements can slide into what Veatch (1973) described as "...generalisation of expertise..." where physicians illegitimately claim authority over value judgements that patients should be allowed to make themselves. Just employing the specific terminology of futility could cause a physician to decide that a specific treatment is not 'medically indicated' and in this way could mask the value judgement. "Futility determinations will inevitably involve value judgements about: 1) whether low probability chances are worth taking; and 2) whether certain lives are of a quality worth living" (Youngner, 1994).

3.7. CONVERSATION VERSUS SILENCE

According to Katz (1984), we have been developing a specific conversation between the patient and the doctor in the western world, whereby the patient is encouraged to take a more active, informed position within the therapeutic decision-making process. It appears that supporters of the futility concept replace this open conversation with the patient with silence. They conclude that they can solve all the difficult questions without discussing them with the patient or her family by relying solely on their professional expertise.¹⁸

It is important to acknowledge that all professional expertise contains value judgements. For example, a report from the Mayo Clinic (1996: 513, cited in Smith, 2000: 129) has reported that many physicians' definition of futility "... includes interventions that might be considered medically reasonable." The report noted that some of the doctors studied, wanted to refuse CPR even though the patient's chance of survival was ten percent or greater. The potential for futility decisions to be based on the physician's prejudice or bias was illustrated by the findings that "CPR was more likely to be considered futile if the patient was not white."

3.8. PROFESSIONAL INTEGRITY

It has been shown that in vital decisions the patient's autonomy and self-determination should be respected. If, however, the physician in charge is determined that his decision carries more weight than the patients' or patients family's, to what principle could one apply to justify overriding the patient? Brody (1994) proposed professional integrity as a relevant principle in this scenario. Professional integrity can be regarded as a key principle, expressing the physician's commitment to a core of moral standards. There are some general assumptions typically associated with such physician integrity.

¹⁸ It would be worthwhile to review Richter's 'Gottes Komplex' here again.

I would suggest that there are three fundamental principles underpinning the conception of medical integrity. Firstly, the primacy of patient welfare that dates back to ancient times. This involves dedication to serve the interests of the patient and altruism that contributes to the trust that is central to the physician-patient relationship. Neither market forces, nor societal and administrative pressures should compromise this principle.

Secondly, there is the principle of patient autonomy, as discussed above. This principle requires the physician to be honest with patients, empowering them to make their own informed decisions.

An thirdly, there is the principle of social justice that can be interpreted as physicians having to be committed to the task of eliminating discrimination within health care, whether this is based on race, gender, socio-economic status, ethnicity, religion or any other social category.

Besides these three fundamental principles other professional responsibilities and commitments could be summarized under the following headings (Medical Professionalism in the New Millennium, 2002):

1. Commitment to professional competence and excellence.
2. Commitment to honesty with patients.
3. Commitment to patient confidentiality.
4. Commitment to maintaining appropriate relations with patients.
5. Commitment to improving quality of care.
6. Commitment to improving access to care.
7. Commitment to a just distribution of finite resources.
8. Commitment to scientific knowledge.
9. Commitment to maintaining trust by managing conflicts of interest.
10. Commitment to professional responsibilities.

I suggest that two aspects of particular importance are to be considered here while discussing the concept of medical integrity. Firstly, we need to consider that medical integrity could be independent of patients' autonomy and their level of medical understanding. So that it cannot be misunderstood to imply that if patients have adequate knowledge that the doctor should necessarily comply with their demands, i.e. an unnecessary operation, such as a routine infant circumcision or unnecessary and potentially harmful medical treatment such as the demand to prescribe steroids for a teenage body-builder. Instead, in addition to respect for patient autonomy, the practitioner should subscribe to medical standards that are completely independent of patients' preferences. Physicians, as a specific professional group should have a legitimate determination of such standards. The final choice for a specific treatment therefore, could be the result of an intensive dialogue between an informed patient with her integer physician. Such a situation would allow room for a referral practice of patients who choose to insist on a treatment that clashes with the physician's position of true integrity.

Secondly, the professional credo should equally be independent of the physicians' personal value system. One could illustrate this by imagining two physicians, one religious and the other agnostic. Their value-systems could essentially be quite different, even though both would adhere to the same professional standards of medical practice. Therefore, it makes sense to speak of an inherent medical standard of practice.

The ethical goals defining such a medical practice of integrity should include promoting health and preventing disease; healing and curing disease, and relieving suffering caused by disease symptoms and as well treatment options. If a treatment can be reasonably predicted not to achieve any of these conditions, then no physician should be forced to offer it, since such treatment requires her to act contrary to her professional credo (Miller, 1995).

Physicians are obliged to adhere to high standards of competence. This is certified by examinations by peers and more recently a continuing medical education programme.

Employing treatment options that predictably will not have a positive outcome deviates from that standard of competence.

Physicians are also obliged to represent standards of scientific knowledge to the public in a truthful manner, claiming only what their treatment can hopefully deliver. Reasonable people will conclude that if a physician offers a treatment, it must have a significant chance of success, which is often called a therapeutic misconception. Thus, physicians who employ such futile treatments contravene the professional credo and could risk becoming quacks or frauds. Here one could again mention the controversy of standard neonatal circumcision, particularly when it is propagated to be performed without anaesthesia.

Physicians are only justified to risk harm to their patients when the possible benefits strongly outweigh the risks such as in treatable cancer. If there is virtually no objective benefit, then there can be no justification to put patients at risk of harm. To demand futile treatment could thus force physicians to become agents of harm and would contravene the professional credo as discussed above.

The above-mentioned case history of Baby K is a good illustration of the important points discussed about professional integrity. A physician should not have to serve a particular goal if it is antithetical to the medical standards that have developed and been approved by the greater medical community (GMC). Therefore, no physician should be forced to apply demanded, but futile treatment to achieve dubious goals.

What do we mean by GMC and what does it represent? In my opinion, it should consist of all physicians who have contributed during their professional life to enrich medical practice. It is a dynamic community who is constantly striving to improve diagnostic and therapeutic skills as well as reflecting on the broader medical goal and appropriate professional and moral behaviour.

3.9. PATIENT INTEGRITY AND THE ABUSIVE CHARACTER OF FUTILE TREATMENT

In a similar metaphorical sense, the concept of patient integrity, sustained by a general community of persons, should be emphasized. No patient should have to endure treatment, which would contradict her life values and no physician ought to invade a patient's privacy and break her integrity with over-zealous, aggressive, inhumane, abusive or futile treatment.

"Karen Quinlan represents one of America's most famous cases of medical ethics" (Gregory & Pence, 1990: 3). She is a paradigmatical case for the above argument and represents "...a larger-than-life symbol of tragic dying." After she had fallen into an irreversible coma, her adoptive family reached the conviction that the respiratory support should be withdrawn. After an exhausting legal battle, Karen was transferred to a nursing home, where she was maintained for more than a decade to die from pneumonia on June 13, 1986.

Karen's story highlights the challenges of resolving conflicting standards of morality within the health care system. Her treating physicians argued from a catholic position of sanctity of life and opposed the wish of the parents to withdraw the respirator. The Quinlan family argued that their adoptive daughter had already died and that there was no prospect of improvement of a poor quality of life and that their daughter, who used to be an active, outgoing young adult, would not have wanted to be kept alive in the condition she was at that point.

In addition, the legal perspective and implications affecting the resolution of a moral conflict as demonstrated in the Quinlan case, have to be considered. This however, is beyond the scope of this thesis.

3.10. THE NEED FOR A DELIBERATIVE MODEL

Metaphorically the futility debate could be likened to the ‘sword of Damoclès hanging over our heads. When Damoclès offered Dionysus all good things in life, Dionysus looked up from the enticing and richly decorated table to see a sword hanging on a string of horsehair over his head. He pleaded with God to have him released (Jens, 1958: 29). The physician-patient relationship has frequently been described as an often-conflicting power-dichotomy. Such polarity seems nevertheless unnecessary and undesirable.

An extreme interpretation of patient autonomy has been to deny any room for physician decision-making (Lelie & Verweij, 2003). Such an extreme approach has often been called the ‘informative or engineering model’ of the patient-physician relationship, where the “... physician’s role is to disclose factual information about diagnosis, prognosis, treatment options, etc. A patient’s role, on the other hand, is to inform his or her physician about values and preferences concerning treatment.” The assumption here seems to be that all value-judgements should be the patient’s responsibility (Bosk, 1992).

Such assumption becomes illusory, since value-free information is impossible to attain (Veatch & Stempsey, 1995; Veatch, 1972). More importantly, the informative model impoverishes the patient-physician relationship. Firstly, it discourages doctors from empathizing with their patients as an empathetic attitude is undesirable and negatively influences the doctor’s professional attitude.¹⁹ Secondly, it stops from the beginning any discussion between the patient and doctor, preventing doctors from questioning perceived strange and irrational patient treatment-demands and preferences. Thirdly, it prohibits physicians from sharing their acquired personal experiences and moral beliefs. Fourthly, it completely misinterprets patients’ preferences as ready-made and given. It does not acknowledge or allow patient preferences to develop or to be adjusted during the course of illness and therapy. Fifthly, it deals with the patient-doctor relationship, the respective preferences and

¹⁹ It is important to mention, that this is still a favoured attitude taught at medical schools worldwide.

attitudes as if there is no overall, encompassing societal good to be considered. It completely ignores that both patient and doctor have their preferences imprinted by society and need them to be adjusted from time to time by the overall good of society.

Paternalism as the opposite of the informative model has been already debated. Both models are inadequate for addressing the complex clinical problems and therefore are undesirable.

Lelie et al. (2003) suggest that the dichotomy be abandoned altogether to favour a model of deliberation, where patient and physician interact, share and finally make the decision together. Both parties ought to accept moral responsibility to arrive at a decision through interactive deliberation. The process of deliberation could transcend both identities' narrative and limitation to conclude with a resolution on a transcended higher level derived from perceived power dichotomy or dilemma. This solution is more than just a consensus of the two positions.

One criticism against such a demanding model of deliberation could be to point out patients' vulnerability and dependency on doctors and their medical care. Lelie (2003) points out, however, that such dependency is an inherent part of all patient-doctor interactions and emphasises the equal dependency of the doctor on the patient. This reciprocal dependency should invoke "... a [mutual] responsibility to see that the patient's perspective is fulfilling its share in the deliberation."

According to this deliberative model, no doctor should unilaterally invoke a futility judgement as a trump card against patient's autonomy. Instead, a patient's request for ongoing life-sustaining treatment could serve as a "... starting point for further exploration and deliberation." A futility judgement can never be a full justification to implement a specific action, since it requires further explanation in terms of values, perspectives and treatment goals. These futility judgements should therefore never end a discussion, but rather serve as a starting point. The deliberative model highlights the urgent need for a democratisation of medical institutions.

A recent American study (SUPPORT Principal Investigators, 1995) found serious deficiencies in the willingness of many physicians to talk to seriously ill patients and their families about wishes for treatment at the end of life. This was a two-phase prospective study aimed at improving end-of-life decision-making. Phase 1 consisted of a two-year prospective observational study of 4301 patients, documenting the degree of patient-physician communication, the frequency of aggressive treatment at the end-of-life, and the characteristics of hospital death. Phase 2 consisted of a two-year controlled trial of 4810 patients and their physicians, randomised to an intervention group or a control group. Physicians in the intervention group received daily estimates of six-month survival, outcomes of CPR, and the estimated functional disability at six months. During phase 1, serious deficiencies in willingness to talk to patients and their families were found among physicians. Furthermore, the intervention protocol of phase 2 failed to improve communication or patient care.

Evidence such as presented in the above trial suggests that a lot of hard work, such as research, medical training and implementation of policies, particularly in the area of palliative care, is urgently needed, I would like to suggest that one potential source for a solution to this problem may be gathered from the, generally under-regarded, African point of view.

3.11. AN AFRICAN PERSPECTIVE²⁰

The African purpose and idea of morality is that of human well-being within a community. Relationships are crucial and are underlined by the absolute equality of all human beings (Tangwa, 1996; Agyeman, 2000). The weak, the poor, the deformed, and the physically handicapped are particularly respected because of a belief that such persons usually possess extraordinary 'depth', have unusually powerful personal spirit-gods, or are frequently used as disguises by the spirits or by God. "... Nso' morality [tribe in Cameroon] is ultimately and fundamentally human—

²⁰ For a discussion if 'African Philosophy' exists and the troubled reflection of Western Philosophy over it, see Ramose (2003).

centred in so far as its teleological end and limits are defined by human well-being” (Tangwa, 1996).

Well-being is so central to their outlook, that they prefer death to suffering. “‘A si ngeh bong kpu’ means death is preferable to suffering” (Tangwa, 1996: 194). With ‘fedee ne owuo a nee fanyinam owou’ the Akans similarly express that they prefer death “... given humiliation or indignity versus death” (Agyeman, 2000: 204).

“A good death would be defined as a relatively painless one that is neither premature nor overdue” (Tangwa, 1996: 195). At advanced age, Africans fear illness and suffering, thus, they would object to sustaining life by artificial means. For a terminally sick patient it would be morally acceptable “... to seek and be helped to find a gentle and painless release from meaningless pain and suffering” (Tangwa, 1996:197). It would however be morally unacceptable to terminate one’s own life (Agyeman, 2000; Tangwa, 1996).

Concluding his essay, Tangwa makes the following plea: “Africans have benefited from western culture and used it to enrich their indigenous cultures. But, unfortunately, in so doing, Africans have also neglected some vital aspects of their own indigenous cultures which could, in turn, have helped to humanise and enrich western culture. As there is no possibility of Africans imposing these putative benefits of African culture on Westerners through any putative ‘blackman’s burden’ and ‘decivilising mission’, it is really up to westerners to salvage these elements of African cultures for the enrichment of western culture and the benefit of humankind, since western culture is, indisputably, the overwhelmingly dominant culture of our historical epoch” (1996: 199). Such reciprocal cultural exchange could create a narrative for those areas where dichotomy is in need of transcendence, as pointed out by Lelie et al. (2003).

I am of the opinion that this possibility warrants further analysis and would suggest such by, for example, reflecting on the concept of Ubuntu.

Before I conclude the discussion of medical futility, I would just very briefly like to present some futility policies, which have been developed mainly in the USA.

3.12. FUTILITY POLICIES

A few hospitals, particularly in the USA, saw a need to create and implement futility policies as a means to manage the different contingent issues involved with medical futility. The American Medical Association has suggested a four-step process in implementing medical futility policies (American Medical Association, 1998).

1. Prior Deliberation of Values.

Sincere attempts should be made to deliberate and negotiate prior understandings between patient, proxy and physician on what constitutes futile treatment, and what falls within acceptable limits for the physician, family, and possibly the institution.

2. Joint decision-making using outcomes data and value judgments.

Joint decision-making should occur between patient or proxy and physician to the maximum extent possible.

3. Involving Consultant[s].

If disagreements arise, attempts should be made to negotiate and reach a resolution within all parties' acceptable limits, with the assistance of consultants if indicated.

4. Involvement of Ethics Committee.

If disagreements are irresolvable, an institutional committee such as the Ethics Committee should become involved.

If the above process does not lead to a resolution of the conflict, a further two-step process has been suggested. Firstly, it should be attempted to transfer patient care within the same institution. Secondly, should this fail, a transfer to another institution should be facilitated.

A strong philosophy of care seems to be driving many of these different hospital futility policies. This is reflected in the following:

- There is emphasis on comfort care throughout the conflict resolution process and particularly, once the determination of medical futility has been accepted by the patient, the family or the health care surrogate.
- There is regard for the importance of asking what it is that the patient wishes to do, and the health care team's awareness of these patient's objectives.
- The role of educating people about treatment preferences among families prior to the end of life is prominent.
- There is encouragement of communicating what those treatment options may be before the end of life.
- The importance of immediate open communication between providers and patients, families and health care surrogates, and
- The need to respect cultural and religious differences is important.

These guidelines focus on a necessary open and continuous dialogue between the health care team and the patient, family or surrogate. Here it becomes obvious that the involved health care team must have the capacity and the training for opening and maintaining the lines of communication at all times. It is essential that the health care team is particularly sensitive to the patient's dignity, values, religion, and ethnic morality (Moore, 1989).

Chapter 4: CASE STUDIES

4.1. AVOIDANCE OF EMERGENCY SURGERY IN TRISOMY 18 WITH LIFE-THREATENING ANOMALY?

A premature baby, weighing 1200g, was admitted to the Children's Hospital NICU with a suspected diagnosis of trisomy 18 (Edward's Syndrome) and oesophageal atresia with tracheo-oesophageal fistula.

The clinical literature suggests that ninety percent of infants with trisomy 18 will die within 3 months of birth. All long-term survivors have had severe mental and growth retardation (Bos et al., 1992; Paris, Weiss, & Soifer, 1992). Oesophageal atresia is an abnormality occurring in about 1:5000 live births. It is incompatible with survival if untreated but the immediate threat to life is not from the atresia and inability to swallow but from the potential respiratory complications. Many of these babies are of low birth weight, usually small for dates and have in more than half of them other associated anomalies. Aspiration of the blind upper pouch must be prevented but the biggest danger is related to gastro-oesophageal reflux up the lower pouch through the fistula into the trachea.

The operation of choice is a primary end-to-end anastomosis after ligation and division of the tracheo-oesophageal fistula. This procedure should only be performed where there is a specialist team of anaesthetists, paediatric surgeons and nurses, and where there are specialist facilities for postoperative respiratory and nutritional support. A review of the Kenyan practice presented at the 1994 PAPSA (Panafrican Paediatric Surgical Association) conference revealed a 100% mortality (Brown, 2003, personal communication). Within the context of a developed country, "[e]ssentially only severe cardiac anomalies, devastating chromosomal abnormalities, and major pulmonary complications significantly affect the eventual outcome" (Filston & Shorter, 2000: 364).

Survival has become the norm and reports look at functional results of survivors. The decision to intervene and to repair the oesophageal atresia with tracheo-oesophageal fistula has to be decided on urgently. Karyotyping of lymphocytes to confirm the suspected diagnosis of trisomy 18 could take however up to three days.

Pondering about the right moral attitude to adopt, when suspecting trisomy 18 in a newborn with other life-threatening anomalies, a number of ethical questions arise. Should the patient undergo aggressive and invasive treatment? Should rare resources be used knowing that the patient's condition is ultimately fatal? Could the parents demand life-sustaining treatment against the counsel of the treatment team?

Various treatment options could be regarded appropriate in such a situation. Firstly, the medical team could decide to repair the oesophageal defect or create a feeding gastrostomy with or without repairing the fistula. The argument justifying this decision would be to facilitate home care and natural feeding. This decision is supported by the argument that an oesophageal atresia repair is standard paediatric surgical practise with generally good outcome.

The question, which needs careful consideration, is what should be done if anaesthetic or surgical complications should develop intra- or post-operatively? Intra-operative ventilation could become extremely difficult, requiring CPR. Since an intra-operative death is a non-natural death with legal implications, most medical teams would typically attempt CPR. How long should post-operative ventilation be offered? If a major disruption of the oesophageal repair, having a high morbidity and mortality, becomes apparent post-operatively, would the surgical team have the obligation to re-operate to correct the complication? If the baby develops pneumonia, are antibiotics indicated? Should total parenteral nutrition be added, if the baby cannot feed within days? What ought to be done if the NICU bed is required for another baby with a better prognosis? Do we have to debate all these questions with the parents and include the conclusions on the consent form, for example that the baby will not be ventilated post-operatively?

Many have argued that it is pointless to treat a baby with such a hopeless prognosis. Ramsey (1970: 133-134) wrote, “[w]hen death is inevitable, further aggressive interventions cease to be treatments and become a painful abuse of the patient.” Who however decides when death is inevitable and what is the value of being alive for a few days, weeks or months?

Moore (1989) provides a partial answer to the above questions when he writes, “[m]edicine must offer the patient more than pain, suffering and costs.” He finds it therefore wrong to attempt “... desperate measures for desperate patients [or parents] desperately hopeless from the outset.” What is called for is not a technological answer for a physiological challenge and thereby prolonging the process of dying but a conscious shift to comfort care and palliation. Many physicians struggle with this very paradigm shift from curative to palliative care.

In the past decade medical, ethical, and legal commentators have sorted through the various ‘Baby Doe’ proposals (Which Baby Shall Live, 1985; Euthanasia And The Newborn, 1987). It seems that a consensus is emerging on what the ‘best interests’ of the child involve, namely that one needs to reject the insistence of maximal life-sustaining interventions for every infant regardless of diagnosis or prognosis. The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research (1983) argued that there are times when the patient’s condition is such that further life-sustaining medical interventions may be foregone.

Finally letting such patients die may not be executing our ethical conviction. Perhaps we ought to help them to die by shortening their suffering. A strong correlation has been suggested between improved coping of families and euthanasia of a significant relative, compared to natural death of the latter. A recent research study from the Netherlands (Swarte et al., 2003) assessed 189 bereaved family members and close friends of terminally ill cancer patients who died by euthanasia, and 316 bereaved family members and close friends of comparable cancer patients who died a natural death between 1992 and 1999. The family and friends of cancer patients who died by

euthanasia presented with fewer traumatic grief symptoms, fewer current feelings of grief and fewer post-traumatic stress reactions than the family and friends of cancer patients who died of natural causes. These differences were independent of other risk factors.

The authors state that their results "... should not be interpreted as a plea for euthanasia, but as a plea for the same level of care and openness in all patients who are terminally ill. This is a crucial point that needs further exploration.

4.2. A CASE OF ACTIVE EUTHANASIA FOR SHORT BOWEL SYNDROME

THE NO HOPE / NO CHANCE SITUATION

"Treatment is delaying death; it is not improving life quality or potential. There is no legal obligation for a doctor to provide any medical treatment if it is not in the best interests of the patient. Indeed. If this is done knowingly (futile treatment) it may constitute an assault."

Royal College of Paediatrics and Child Health

"We have, in fact, two kinds of morality side by side: one, which we preach but do not practice, and another which we practice but seldom preach."

Bertrand Russell

Jacob²¹ was born at 37/40 weeks gestation as the first child to a young religious couple. Shortly after birth, with the first attempts at breastfeeding, it became evident that there was a serious problem. He could not keep his milk down and progressively vomited milk mixed with bile. He was born prematurely, with a birth-weight of 2,5

²¹ The name of the patient has been changed to keep confidentiality

kg. Physical examination did not reveal any major abnormality. The abdominal x-ray findings showed a double bubble sign that is paradigmatic for intestinal obstruction at the level of the duodenum.

At surgery, multiple small bowel atresias (5 atresias in total = type IV)²² were found within the first 6 cm of the small bowel. The critical finding was that after the surgery he was left with a total of 12 cm small bowel (including the duodenum). He had an intact ileo-caecal valve and a normal colon.

Short bowel syndrome (SBS) is a condition, defined by the length or absorptive function of the small bowel, e.g. a residual length of the distal small bowel (jejunum and/or ileum) of less than 75 cm, without including the duodenum or colon. “Although many factors influence survival, long-term survival is possible in infants with an 11-15 cm jejuno-ileum and an intact ileo-caecal valve or 25-40 cm small bowel length without an ileo-caecal valve” (Millar, Rode, & Cywes, 2000: 419). It is important to realize that these are overseas data!

The surgeon’s immediate reaction was that Jacob did not have enough small bowel length to become independent from artificial feeding. A discussion developed in the operating theatre. The main question was, if one should repair the defect or should leave it alone in consideration of the poor and futile outcome. Further consultation was engaged with the head of the academic Paediatric Surgical Department. On his advice, the defects were corrected and Jacob referred to the University Children’s Hospital for post-operative management.

He recovered uneventfully and was given total parenteral nutrition (TPN: intravenous, artificial feeding). An ad hoc Ethics Committee with involvement of various role-players (different paediatric medical and nursing staff) was convened. It was decided to give him a treatment trial of 3 months, during and after which his condition would be reviewed. According to the prognostic factors (Sonderheimer et al., 1998) applied at 3 months of age, there was sufficient indication at that time that

²²Atresia is the medical term for a medical condition where the bowel has a complete mechanical obstruction. Atresias are classified into five different types, whereby type IV means multiple atresias.

he would be able to sustain his life. His treatment was continued and today Jacob is a healthy boy and has an excellent quality of life. The burden of his condition and the constant absence of the mother, who was most of the time in the hospital with her child, might have lead to the divorce of the parents.

Petrus²³ was admitted for investigations of biliary atresia to another academic hospital. He was 2 months old and deeply jaundiced. While he was waiting for his blood results, he had an acute event, whereby he started to vomit profusely intestinal contents and developed a serious abdominal condition. His abdominal operation confirmed the preliminary diagnosis of biliary atresia, which is a very serious condition where the extra-hepatic bile ducts are involved in an inflammatory process and progressively vanish, leaving the liver congested and prone to fibrosis and progressive cirrhosis. At the same time, he had a midgut volvulus (twist in the mesentery of the small bowel, interrupting the blood supply to the midgut) with most of the midgut being severely compromised and at least 80% being dead and non-viable.

For the purpose of giving the infant a real chance of recovery, the twisted mesentery was untwisted, a liver biopsy for confirmation of biliary atresia taken and the abdomen closed. Postoperatively he was sent back to the ICU for further active management with the plan to reassess the possible recovery of the small bowel at a re-look operation 48 hours later. Counselling the parents and extended family, they were given information about the two conditions, after which a discussion about the potential for a composite (liver and small bowel) transplant ensued. The liver-transplant team who were asked for their expert advice, declined to take over potential further treatment.

At the second operation, it was found that his small bowel had not recovered, but instead actually had deteriorated even further. Theoretically, his only chance of survival would have been a liver and small bowel transplant, which at the present moment is unavailable in South Africa but seems to have evolved according to

²³ Again not his real name.

Kosmach (2003) "... from an experimental strategy to a feasible alternative ..." with a long term survival rate of just over 50%.

The parents, together with the extended family, were counselled and given ample time to deliberate amongst themselves. Finally, they reached the conclusion that the baby should be extubated once the whole family has left the hospital. The explanation for this request was that it would have been an unacceptable cultural practice for the mother to stay behind and hold her child in her arms for purposes of comfort care after the extubation. According to their belief this would have brought bad luck onto the mother and through her onto the father. This cultural belief is related to pollution beliefs around death and has implications for her relationship to her husband afterwards.

The baby was extubated, but survived for another three long and distressing weeks, causing consternation and doubts about the clinical assessment and the approach followed. TPN was withdrawn, but the intravenous fluids that were the likely reason that the infant survived such a substantial amount of time, were continued.

A review of the local experience with the short bowel syndrome (unpublished data) revealed that in the last 25 years *there was not a single survivor locally with a small bowel length of less than 20 cm*. Fifty-six medical records of children with short bowel syndrome were analysed (1979-1993). There were 39 survivors and 17 deaths. The 39 survivors received a mean of 137 days (range 7-694 days) TPN. Seven children out of the 17 non-survivors did not receive any treatment. Their mean length of small bowel was 11 cm (range of 7-17 cm). The incidence of mortality differed according to the length of small bowel. A small bowel length of more than 50 cm had a 12% mortality (4/34); a length of 30-50 cm had a 35% mortality (4/11) and a length less than 30 cm 82% mortality (9/11). Two patients from the last mentioned group received more than 2 years of TPN before they died.

Jacob had two favourable prognostic factors, his prematurity and the presence of an ileo-caecal valve (point of transition from small bowel to large bowel). It is thought

that foetal small bowel can still double in size in the last trimester, "... from the mean 115 cm at 19 to 27 gestational weeks to 248 cm at 35 to 40 weeks" (Millar et al., 2000: 419). The loss of the ileo-caecal valve however, doubles the mortality (50%/21%).

Because long-term adaptation to neonatal small intestinal resection appears to depend directly on elongation of the bowel, which is accompanied by increased linear growth, it is self-evident that the patient with the shortest residual bowel will require parenteral nutritional support for the longest time. It seems that other factors have an impact on the success of neonates gaining nutritional independence. Accurate prediction of the duration of nutritional dependence solely based on the residual length of small bowel has been for this reason inaccurate.

Sonderheimer et al. (1998) confirm that the small bowel has a capacity to adapt until 40 months. Their study showed that after that time they did not have a single patient who could become TPN independent. Therefore, traditionally the infant would have been given a trial of over 2 years till it becomes clear that further bowel adaptation would be highly unlikely and nutritional independence an impossibility. The infant's tolerance for enteral feeding, as a proportion of the total daily energy intake, was a significant predictor of duration of dependence on TPN. Their paper allows prediction of expected durations of TPN for patients with any combination of the two significant variables of length of small bowel and percentage of daily enteral energy intake at 12 weeks' adjusted age.

The clinical situation is further complicated by the fact that treatment itself, such as TPN, could have severe complications. Most commonly encountered problems are recurrent central line infections, cholestasis that may progress to liver fibrosis, cirrhosis and liver failure.

Petrus' situation on the other hand is quite different. He had nothing in his favour, since he was already 2 months old and there would have been no chance that any recovering bowel would have lengthened in time. The second serious condition of

biliary atresia was an additional limiting factor for any chance at a normal life. Biliary atresia is a progressive disease. Many of these infants have definite excretion of bile at birth, but develop jaundice due to a progressive inflammatory condition that leads to a complete biliary obstruction. Once the diagnosis is confirmed, a porto-enterostomy, a so-called Kasai²⁴ procedure, can be performed. In simple terms, this procedure makes it possible that the obstructed intra-hepatic bile ducts drain into the small bowel.

Initially, about fifty percent of infants will have a good response, going on to ages 4 or 5 years with good bile flow. Thereafter however, the ongoing progression of liver fibrosis will lead to cirrhosis and complications from portal hypertension, such as bleeding episodes from oesophageal varices that finally necessitates a liver transplantation. Ultimately less than 20% of those who have had a porto-enterostomy will survive to adulthood without the need for a liver transplant.

There is some debate regarding the utility of a primary porto-enterostomy compared to a primary liver transplantation. Many paediatric surgeons in the developed world and all working within the framework of a developing country accept that if a child is seen early, probably before the age of 3-4 months, it is advisable to start with a porto-enterostomy to keep and reserve the liver transplant for those who fail after porto-enterostomy or present late (Sigalet, 2000).

The traditional task of physicians is nonmaleficence and beneficence towards their patients. This is generally achieved by respecting patient or patient-proxy autonomy. Where this would not be possible, physicians would maximize patient's best interests. Petrus' treatment could be considered futile and had the potential to even be harmful. There was no local medical option to save his life, therefore TPN, which is a balanced nutrition necessary for his growth and development, had been correctly withdrawn.

The continuation of intravenous hydration, containing the necessary water, electrolytes and glucose for his maintenance, could sustain his life, at least for a short

²⁴ So called after the procedure's inventor.

period. Such management however seems confused. Futile treatment is withdrawn half-heartedly, and by continuing intravenous fluids, the suffering of the infant, his parents and, equally important, of all the medical staff involved was directly prolonged.

These state of affairs show a deep seated conflict, which the American Association of Paediatrics Committee on Bioethics eloquently expressed, when they wrote that “[a]lthough many health care professionals feel reluctant to discontinue life-sustaining treatments, most philosophical and legal commentators find no important ethical or legal distinction between not instituting a treatment and discontinuing treatment already initiated Continuing non-beneficial treatment harms many patients and may constitute a legal, as well a moral, wrong” (Kohrman, 1994).

Continuing with non-beneficial intravenous fluids thus seems futile. The fluid treatment is not sustaining the patient until a curative treatment becomes available, nor is it treating the disease process itself. His terminal condition is artificially prolonged without hope of improvement. To keep somebody forcefully and hopelessly alive could be considered an assault as well as an abuse of professional authority. There is no evidence that intravenous fluids lessen the infant’s discomfort of hunger and thirst; instead, one could argue that they rather extend the infant’s experience of discomfort.

There could be a strong argument that terminal sedation (Quill & Byock, 2000; Quill, Dresser, & Brock, 1997) or even active euthanasia would have been a more appropriate option. “Terminal sedation is the use of high doses of sedatives to relieve extremes of physical distress. It is not restricted to end-of-life care and is sometimes used as a temporising measure in trauma, burn, post-surgical, and intensive care. Although rendering a patient unconscious to escape suffering is an extraordinary measure, withholding such treatment in certain circumstances would be inhumane. When applied to patients who have no ... prospect of recovery, terminal sedation refers to a similar last-resort response to extreme, unrelieved physical suffering. The purpose of the medications is to render the patient unconscious to relieve suffering,

not to intentionally end ... her life. In the context of far-advanced disease and expected death, artificial nutrition, hydration, antibiotics, mechanical ventilation, and other life-prolonging interventions are not instituted and usually withdrawn if they are already in place" (Quill & Byock, 2000). Before such treatment can be applied, it is vital to have the parents' informed consent and to be in no doubt about the presence of final, severe and intractable suffering.

A counterargument could be that the intravenous fluid was continued with the beneficial aim to ease the parents' emotional pain about their child's terminal prognosis. It might have been an effort not to be too harsh with them by withdrawing all therapeutic interventions at the same time. Such an attempt, as compassionate as its underlying motivation might be, could actually be considered to be dishonest. It gives a false message to parents who might think that the baby is still being treated and that there is hope. It is important to be aware that the primary responsibility remains towards the infant's best interest and only secondarily to care for the parents and other significant others.

On further analysis, it becomes clear that there was a beneficial paternalism at work, a paternalism that is prevalent in the African context as discussed. It is unlikely that the parents were informed about different therapeutic options and that the intravenous fluids were potentially responsible for the protracted dying process of their baby. In a way, their autonomy was not respected. Honest and open self-reflection ought to protect from naïve beneficial paternalism becoming abuse of expert authority.

The debate around the acceptability of withdrawing/ foregoing nutritional treatment at the end-of-life is ongoing. Nearly half of the respondents to a survey of doctors and nurses expressed concern about the acceptability of withdrawing/ forgoing such treatments (Solomon, O'Donnell, & Jennings, 1993). There is a powerful symbolism in feeding the hungry and giving drink to the thirsty. Feeding the hungry has been cited as the most fundamental of all human relationships and " ... the perfect symbol of the fact that human life is inescapably social and communal" (Callahan, 1983).

Moreover, "feeding is the first response of the community to the needs of newborns and remains a central mode of nurture and comfort" (Lynn & Childress, 1983).

Food and water are, in other words, powerful symbols of care and comfort, and through their provision we communicate our compassion and concern for one another. There is therefore a concern that withholding or withdrawing artificial nutrition and hydration will undermine our commitment to the values of care and comfort, both in medical institutions and in society at large.

The focus on the symbolic value of providing food and water may mask several important differences. Artificial nutrition and hydration are provided with the intent to prevent or treat malnutrition and dehydration. Conversely, hunger and thirst can sometimes be treated without resorting to artificial nutrition and hydration. Moistening the patient's lips and mouth with ice chips or glycerine swabs can alleviate the sensation of thirst associated with a dry mouth.

In addition, artificial nutrition and hydration require invasive procedures that strain the symbolism of offering food and drink to those in need. They are supplied through the patient's nose and throat (nasogastric tube), veins (intra-venous line), stomach (gastrostomy), intestine (jejunostomy), or major vessel into the heart (hyperialimentation). All these procedures come at a price that the patient would have to pay by enduring increased suffering induced by the treatment complications.

Finally, rather than undermining the values of care and comfort, withholding or withdrawing artificial nutrition and hydration may actually contribute to the dying patient's sense of comfort. In short, withholding or withdrawing artificial nutrition and hydration should not automatically be equated with "starving the patient to death", and is even considered by some to be a form of compassionate treatment (McCann, Hall, & Groth-Junkcer, 1994; Printz, 1992). It can be concluded then that to stop food and water intake is part of the dying process.

Another debate is whether artificial nutrition and hydration are morally similar to, or should be distinguished from, interventions recognized as medical treatments. Those

who argue that artificial nutrition and hydration should always be provided may contend that they are forms of basic supportive or palliative care, rather than medical treatments aimed at curing a disease (Rosner, 1993). Others claim that artificial nutrition and hydration are not relevantly different from other medical treatments. They are invasive, prescribed by physicians, and administered by health care professionals and should therefore be governed by the same standards (MacFie, 1996).

Withholding or withdrawing artificial nutrition and hydration seems to blur the distinction between killing and allowing to die. Withholding or withdrawing artificial nutrition and hydration might seem not merely to allow the patient to die, but to kill the patient, and therefore be morally suspect. This aspect of the debate is worthy of further research in order to critically analyze the logic of the difference between killing and letting die (active/ passive euthanasia) (Kuhse, 1998; Rachels, 1975). It is an enigma to me, to understand how an extubation, while the patient is still under the influence of muscle paralytic agents, could be regarded passive euthanasia and is generally accepted, while injecting a deadly drug to speed up the undeniable dying process is usually regarded as active and prosecutable euthanasia.

Another point worthy of consideration, is that such futile treatment often ruins the family financially. ICU treatment is very expensive and in private practise, medical aid can easily run out of funds. If the patient is continued to be treated at the private institution, the family can face ruin and personal disaster.

Finally, even though there is great uncertainty about the baby's experience, we nevertheless need to ask ourselves if there is any value to drawing out such hopeless suffering, and whether such hopeless suffering could not be labelled futile. What seems important though, is the acknowledgment of there being a time when a paradigm of cure and healing is appropriate. Such a situation may however change to one which demands a shift to a paradigm of comfort care. Medical professionals are ill equipped and trained for such a shift and they find it difficult to do.

Chapter 5: CONCLUSION

In conclusion, this study has attempted to demonstrate the importance of the concept of medical futility within the broader field of end-of-life decision-making. The exponential growth in medical technology and skill pertaining to medical science generally, and in the NICU particularly, brings with it a growing body of moral dilemmas. Amongst other consequences, these changes have brought about a significant drop in perinatal mortality. New and rapid technological changes, e.g. CPR²⁵, have created pressures for a need to re-examine underlying tacit assumptions of established medical practice (Health Care Ethics Committee of the Health Council of South Florida, 2000; Zweibel, 1989).²⁶ An example of such assumption is the utopian ideology that physicians are fighting death and disease with science lighting the way to a better health for all (Hodgkin, 1996).

Such a situation presents the danger of applying emergent technology uncritically in order to prolong life (or the process of dying). This may be done without restraint, without prior careful and critical considerations of patient factors. One example of such uncritical application is where patients with medically futile conditions are subjected to the uncritical application of technologically advanced interventions, without careful consideration of the induced suffering to the patient and her family, as well as to the health professionals involved. In the extreme, it can become a matter of science for the sake of science, losing sight of other significant aspects of patient care.

It cannot be denied that there are situations where treatment will be ineffective in ameliorating or correcting the underlying condition. The factors most frequently cited by decision-making physicians, are poor prognosis and quality of life. The Royal College of Paediatrics and Child Health published a document in 1997 regarding the

²⁵ The advent of CPR, ICU, ventilator support and TPN have changed the nature of clinical medicine practiced and force us to critically reflect the technology applied. The progress of medical practice is forcing us to make difficult decisions of end-of-life and resource allocation.

²⁶ e.g. the interest in transplantation contributed to an interest in brain-oriented definitions of death, which haven't as yet been universally accepted For a further and detailed reading consult Grodin, MA 1993. Religious advance directives: the convergence of law, religion, medicine and public health. *American Journal of Public Health* 83: 899-903; Paris, JJ, Bell, AL and Murphy, JJ. 1995. Pediatric brain death: dead is dead. *Journal of Perinatology* 15: 67-70.

practice of withholding or withdrawing life sustaining treatment in children. Four points seem relevant to our current discussion:

- a) There is no ethical difference between withdrawing and withholding treatment.
- b) There is no obligation to give treatment, which is considered futile and burdensome – indeed this could be regarded as an assault on the child.
- c) Treatment goals may be changed in the case of children who are dying.
- d) Treatment may be withdrawn if continuation is not in the patient's best interest.

The same document lists five situations where curative treatment may be withheld or withdrawn:

1. The Brain Dead Child.
2. The permanent Vegetative State.
3. The 'No Chance' situation (delaying death).
4. The 'No Purpose' situation (physical and mental disability too great to be acceptable).
5. The 'unbearable' situation (burden too high for quality of life).

Compassionate withdrawal of treatment would require moving from a tactical approach and its associated goal, where the physician focuses on individual interventions, to a strategic approach, where a different overall treatment goal needs to be formulated. The formulation of this treatment goal should be the result of continuous discussions with the parents and the staff. The desired treatment goals and not the availability of technology or the futility of treatment, should dictate the plan of care. This treatment goal should not be taken as an absolute, but rather as a guideline; like a light in a dark room that allows the individual objects to be seen clearly and in the fullness of their context.

Rapid technological progress changes cultural contexts and social structures, which is often overlooked. The western medical paradigm needs to be replaced with a more pluralistic, postmodern, contextual appropriate one, within which healthcare can be delivered. It can no longer be presupposed that physicians, nurses and patients share a common view of the good of life nor that medical practice will be conducted, framed by the Judeo-Christian principles.²⁷

This study has indicated that the dominance of patient autonomy²⁸ has been increasingly challenged and that the concept of medical futility has been central to such a challenge. There is a growing body of evidence suggesting that it is "... consistent with the goals of medicine since the time of Hippocrates [that] physicians not only have no obligation to treat - or even present such options to patients and families - when medical interventions cannot produce a sufficient quality of life, [such as restoring consciousness and the ability to live without continuous life support] but also that physicians cease behaving professionally if they persist even when no medically valid goal remains" (Capron, 1997).

Advocates of patients' rights fear, however, that the application of medical futility could be used as a trump card by the medical profession for expert domination and paternalism over and against patient autonomy and self-determination.

I suggest that a timely paradigm shift is necessary within the growing awareness of the actual limits of medical science's propensity to cure, heal and extend life. A consequence of uncritical acceptance of the advanced possibilities that technology presents to medicine may lead to the fallacy being supported that cure is effected by prolonging life. What may actually often occur instead is that the dying process is prolonged. Such a process may not only prolong suffering, but also actually cause it. Due to the complexity of moral and psychological issues, inevitably involved in such

²⁷ There is a lack of information about African patient's values. An inquiry at the Medical Anthropology Department (University of Cape Town) demonstrated an aporia of knowledge. It can therefore only be concluded that the western scientific paradigm is uncritically accepted when modern clinical medicine is practiced within the South African context. Its applicability within the South African context of multiculturalism has not been analysed to my knowledge.

²⁸ Again, the place of patient autonomy within an African setting is unknown.

situations, all persons involved in the process may suffer. Furthermore, caring based on empathy and sympathy (meaning suffering together), is sacrificed for treatment based on technological imperatives.

It has been argued that technological advances in medicine have obscured the need for human compassion for the dying and their loved ones. There is a growing public demand for a more holistic, integrated approach towards health, illness, death and dying. Furthermore, published literature reports evidence that the quality of end-of-life care is often unsatisfactory for both patients and families (Singer & Bowman, 2002).

It is within this context that the concept of medical futility is positioned, even though it sometimes seems to have a pejorative connotation²⁹ and suffers from ambiguities. I am of the opinion that the concept of medical futility should serve as a catalyst for an open and critical debate amongst all the relevant parties involved in end-of-life decision-making.

As the process of decision-making has always been and remains an essential part of any medical practice, medical personnel do not have the luxury of naively withdrawing from such responsibility. What is required is greater awareness of ethical decision-making, models of communication, conflict-resolution, history taking and assessment of patient values and preferences, as well as training and enabling a capacity to care (empathy) (Goold, Williams, & Robert, 2000; Singer & Bowman, 2002).

In conclusion, five core elements as suggested by Brody (1997) seem to summarize this discussion of medical futility as it relates to end-of-life decision-making:

1. It is important to understand the difference between the futility/ integrity debate and the justice debate. Treatment of little benefit could possibly be considered once it has become cheaper. However, treatment, which violates the patient's or

²⁹ Like other terms which are often used in medical language, such as hysterical or hypochondriac.

physician's integrity should never be provided independent of how cheap it might be.

2. Debating medical futility should not be equated to debating patient autonomy.
3. A deliberative model of medical futility is essential to defuse the major underlying reservations that the concept of futility could be used as a trump card for unilateral withdrawal of life-sustaining treatment.
4. Responsibility and care for patient well-being must outweigh the potential abuse of futility determinations by physician authority.
5. Patients should at all times have the right to a second opinion and access to an open review procedure by an ethical committee.

In spite of the concept of futility having a pejorative connotation, I have attempted to indicate that avoiding the concept altogether is detrimental to the debate concerning end-of-life decision-making. Medical futility could serve as a useful starting point for deliberation of all issues related to such a discussion and could contribute to an evolving patient-physician relationship that could transcend to a higher level of true communication and where novel solutions may be found. Such solutions would have a greater chance of being ethically sound, if all parties involved, such as the patient and his family, the caregiver, and all support involved, could critically and objectively deliberate the dilemmas.

The difficult shift from a paradigm of cure to one of care indicates that there is a need for research and education in quality of end-of-life care. It is ironic therefore, that only very few papers have addressed quality of life care in developing countries. "This is perhaps nothing more than another manifestation of the 90/10 gap – that 90% of medical research is undertaken on those diseases that cause 10% of the global burden of disease" (Singer & Bowman, 2002).

Finally, I hope that the powers in charge of medical training, hospital management and resource allocation will demonstrate their leadership by implementing a framework that is conducive for the ongoing progress of clinical medicine as well as the evolution of our consciousness that should lead to an overall compassion. An

indication of this deeper awareness of the moral intricacies that the practice of modern clinical medicine brings with it, and that this demands answers to very difficult ethical questions, is reflected in the written question that was asked at the recent Certificate Examination in Paediatric Surgery of the College of Surgeons (2003): “[d]escribe your understanding of the concept of “futile care” as it pertains to paediatric surgical practice a) [u]nder what circumstances would you consider it appropriate to withdraw active treatment to a critically ill child? b) What do you consider to be essential basic care? [and] c)[w]hat are the medicolegal implications of withdrawal of care in the South African context?

I conclude that the physician practicing good medicine realizes when the limit of technology has been reached, when further attempts to save life are futile. It demands the realization that there comes a time for the physician’s role to change from trying to save or prolong life, to trying to provide the best possible quality of life and care for the patient in his remaining time. This should by no means be looked upon as abandoning the patient, but rather as giving the patient and the family an opportunity to come to terms with, and be at ease with the dying process. It is the responsibility of the treating physician to guide this process by demonstrated sensitivity and compassion, in addition to medical skills, when accompanying all parties involved through to the final stage of end-of-life decision-making.

FIGURES:

Figure 1 shows the cost-benefit relation, where declining treatment efficacy is coupled with increased cost (financial as well personal) and shows how such treatment can become a burden (marginal utility). This marginal utility forces society to apply stringent criteria for resource allocation. Medical professionals are directly exposed to these convergent societal demands. Patients expect high standards and innovative medical therapy on the one hand, yet on the other, socio-political forces demand sensible and rational use of the limited resources. This creates tension and can potentially clash with patient autonomy.

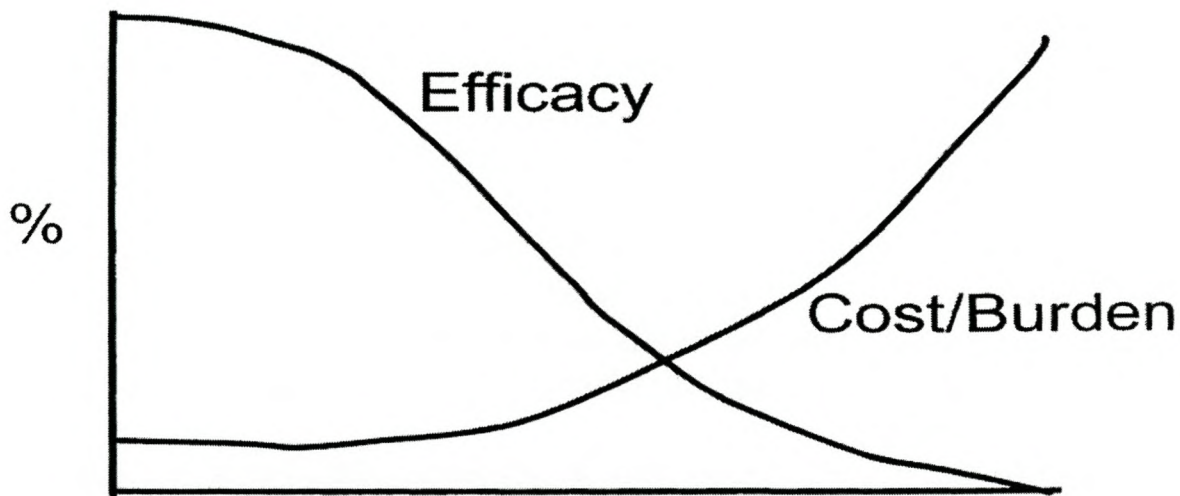


Figure 1. Marginal Utility adapted from Avery (1998).

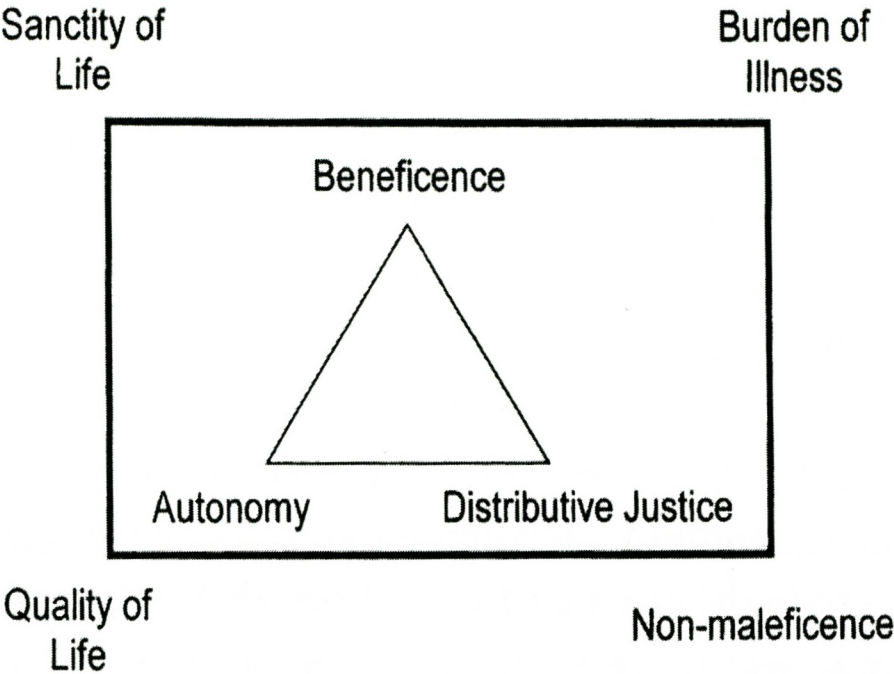


Figure 2. The tensions of moral principles considering withdrawing or withholding life-sustaining treatment adapted from Avery (1998).

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